PARENTS OF CHILDREN WITH CEREBRAL PALSY: THEIR EXPERIENCES AND PERSPECTIVES OF CONDUCTIVE EDUCATION

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ABSTRACT

Some parents of children with cerebral palsy choose a non-traditional programme of education for their children – Conductive Education. Many countries appear to have welcomed not only research into Conductive Education but also the practice of this alternative programme of education for children with cerebral palsy (Lebeer, 1995; Weber, 1995; Cooper, 1986; Sigafoos, Elkins, Hayes, Gunn, Couzens and Roberts, 1991; Dowrick, 1993; Bochner, Center, Chapparo and Donnelly, 1996 and Hass, Takuziner, Hendelsman, Ginzberg and Ornoy, 1997). In the U.K., whilst Conductive Education has, for some years, been largely ignored by the professional and academic world (Sutton, 1998), the current national position suggests an increase in academic interest due to emerging training schemes and also, paradoxically, because of increased awareness outside of the U.K. The most rigorous study to date (Bairstow, Cochrane & Hur, 1993) although receiving much criticism regarding its design and methodology (Stukat 1995, Catonese 1995, Lie & Holmes 1996) rapidly assumed the status of the definitive statement on Conductive Education and as a consequence Llewellyn, Owens & Hogan (1997) highlight the need for research to move away from the effectiveness or parents' satisfaction with a programme of Conductive Education to explore their perceptions.

In order to add to the body of knowledge in this field, the perceptions of parents on Conductive Education are explored through the application of two methodologies – Grounded Theory (Strauss & Corbin,1990) and Discourse Analysis (Potter & Wetherell, 1994). Parents from eleven family units, who had enrolled their children on a programme of education at The National Institute for Conductive Education in Birmingham, were interviewed. Unstructured, in-depth, tape-recorded interviews were parent-led with regard to location and duration. A structured application of the grounded theory method of enquiry is applied to the data and the theoretical implications that emerge highlight a temporal shift in the data leading to parents becoming experts in issues related to childhood disability and programmes of education. Parents reclaim ownership of the decision-making process (which they have hitherto perceived to be out of their control) and orchestrate the identity of their children by choosing a programme of Conductive Education as practised at the National Institute for Conductive Education in Birmingham. Application of Discourse Analysis to

documentation in relation to the decision-making process to further extend the theoretical implications revealed three discourses in operation – objectivity versus subjective experience, negativity versus positivity and current disability versus potential ability. The theoretical implications related to these discourses are concerned with parents as equal partners in the decision-making process and the differential between parents and Local Education Authorities on the fundamental underpinnings of an appropriate programme of education for children with cerebral palsy. The findings from the application of each methodology are brought together for discussion and conclusions drawn.

Theoretically it is argued that positivistic approaches to research in this area which either exclude the voices of parents or, if included, restrict the voice to issues of satisfaction with a programme of Conductive Education, serve to ensure that education for children with special needs is pathologised. It is argued that the pathologising of education for children with special needs serves the interests of existent dominant government providers of programmes of special education.

Contents

Chapter Three: Towards an appropriate methodology

Chapter four: The Tactics Identified - Grounded Theory Applied

APPENDICES

Tables **Page Number**

Figures **Page Numbers**

CHAPTER ONE: Introducing the Research

"C was in the system in the early days...you go a certain way and in my opinion lots of cerebral palsied kids go forward the same way.."

1.1 Introduction to the Problem

Research into childhood disability in general and programmes of education for children with disabilities in particular have often ignored parents' vast store of knowledge about their child and, in instances where their opinions are sought, these are often under-valued because, to parents, "all geese are swans" (Hall and Hill 1996).

Educational provision for children with cerebral palsy can be problematic for all those involved. This is especially the case from the perspective of the parents for four main reasons. Firstly, because the diagnostic term 'cerebral palsy' covers a wide range of childhood disabilities. Secondly, the ultimate choice of education for children with special needs lies with Local Education Authorities which leads directly to the third reason - the existence of an alternative, non-traditional programme of education for children with cerebral palsy outside the purview of Local Education Authorities (LEAs) - Conductive Education. The fourth reason is that Conductive Education is not freely available to parents as a choice of education for their child with cerebral palsy.

Two reasons for educational provision for children with cerebral palsy being problematic from the perspective of parents, from a survey of the literature, seem to stand out above all the rest:

- parents do not perceive disability to be a limiting factor to progression through an

appropriate programme of education; and

- the opinions of parents are undervalued.

Prior to 1987 parents' options were limited to LEA provision. Since 1987, when Conductive Education was first introduced in Birmingham, parents who had heard of this alternative, non-traditional programme of education also had a choice outside of their LEA provision. However, parents choosing this alternative programme of education for their child and requiring their LEA to fund the education outside of their special educational provision, had to justify their choice. LEAs seldom agreed with the choices these parents made and, more often than not, resisted requests for funding.

With regard to research, investigations into childhood disability in general, whether concerned with the study of the disability itself or the interaction between a child with a disability and the family unit, have, nevertheless, usually concentrated on one single area of enquiry. For instance, Nordenfelt (1995) has focussed on the importance of society's ability to classify disability through characterisation. The suggestion here is that ability (and subsequently disability) can be conceptualised in order to enhance and inform social and/or medical policy-making. Similarly, Sim, Milner, Love and Lishman (1998) concentrated on a single issue of enquiry by considering the definition of need through examination of current frames of reference.

A further single aspect of enquiry has been that of the psychological effect of disability experienced by an individual. Livneh and Antonak (1994) view such enquiry as a basis for informing clinical interventions whilst Vargo (1978) explores the importance of the role of occupational therapy in the successful psychological adjustment of an individual to a disability. Similarly, Peganoff (1984) suggests that an occupational therapy programme that meets the social as well as therapeutic needs of an individual is

essential for the enhancement of functional status. With regard to physiotherpay, however, Bower, McLellan, Arney and Campbell (1996) carried out a controlled trial of different levels of physiotherapy and have suggested that, whilst intensive therapy produced a slightly greater effect in motor skill, the use of specific measurable goals was possibly of greater importance.

However, Llewellyn and Chung (1997), whilst also exploring psychological issues of disability narrow the focus further by concentrating on factors affecting self-esteem. In this instance emphasis is placed on the importance of *not* assuming that disability necessarily leads to problems in self-esteem. Also brought into question is the appropriateness of the use of psychometric measures of self-concept with individuals with disabilities. The role of professional rehabilitation has also been considered to be of great importance with regard to how an individual reacts to changes in body image as a result of disease or injury (Drench, 1994).

Factors affecting the independence of individuals with disabilities have also been considered (Bleck, 1990) and have centred around issues of culture and life-style. In this case the findings suggest that the independence of an individual with disabilities can be greatly affected by the environment and cultural aspects of every-day life.

However, investigations into issues of childhood disability have not only focussed on frames of reference and psychological effects on the individual, several studies have also considered cognitive issues of disability of relevance here because the definition of cerebral palsy is often related to disease or damage to the central nervous system (Read, 1995). For instance, Kempermann and Gage (1999) suggests the possibility that the human brain is capable of producing new nerve cells as late on as adulthood which

could be of particular relevance to the study of cerebral palsy if this is indeed the case. An understanding of 'normal' cognitive processes has also been undertaken by Caramazza (1986) by consideration of what is considered to constitute the impaired cognitive processes of brain-damaged individuals. These findings suggest that although a single-case approach to such enquiry is not unproblematic, this approach is essential in gaining an understanding of the issues involved. Also with regard to cognitive issues, Lebeer (1998) suggests links between the possible plasticity of the brain and the learning environment to which an individual is exposed. In this sense the opportunity of areas of the brain being able to compensate for damage is dependent upon the type and nature of learning experience.

It is also possible to draw similarities between Frith's (1992) model of cognitive deficit with regard to autism and the abnormality of the brain associated with cerebral palsy. In this sense, the abnormality is not viewed as being responsible for the lack of interaction with the environment (such as immediate or spontaneous response) but rather, the lack of a medium to delivery information in an appropriate manner thereby enabling an individual to interact with the environment is held to be of primary importance.

With regard to enquiries related to childhood disability and issues of education, the trend has been to focus upon the integration of children with special needs into mainstream schooling. For example, Allan (1996) stresses the importance of shifting the focus from the *amount* of integration taking place to attempts to gain an understanding of the discourses involved. In this instance, discourses are viewed as serving to construct the experience of children with special educational needs in the situation of mainstream schooling. Middleton (1999) on the other hand suggests that attempts to integrate are undermined by the increased involvement of voluntary

organisations as providers of education. However, integration is also supported by Kitchen (1998) whereby the message that inclusion would represent to individuals with disabilities is viewed as central to issues of integration. Kitchen suggests that the segregation of pupils is a form of protecting the non disabled community from the disabled community and vice versa with the overall suggestion that space itself is socially produced.

A further point (to be developed in chapter five) is put forward by Sutton (1986a) suggesting that children who have experienced a programme of Conductive Education will require a different level of continuing special needs when integrated into the mainstream schooling system.

There has also been the suggestion that pupils and parents tend to find themselves marginalised and possibly devalued during the process of integration due to an environment which Bagley and Woods (1998) consider to be driven by instrumental values which do not in fact reflect the needs of pupils.

The review of the literature, so far, has been concerned with many diverse issues with regard to childhood disability in general although these have, nevertheless concentrated on specific aspects of enquiry. However, investigation has also been carried out into childhood disability which includes the family unit as an element of enquiry. For instance, Quine and Rutter (1994) concentrated on factors which affect the diagnosis of a child's disability and emphasise the importance of the timing of a diagnosis as well as how the information is imparted. It appears that many parents report dissatisfaction with the doctor-patient communication and the need for improved measures is highlighted.

A further focus has been the possibility of childhood disability representing a source of grief or loss to parents (Bruce and Schultz, 1994). Central to this enquiry is the notion that parents grieve for things that might have been (in terms of the 'normal' child) and that this grief is a part and parcel of parenting a child with disabilities. In the same vein, investigations have explored the idea that parents' relationship with their child results in feelings of chronic sorrow caused by the disability of a child not being the 'hoped-for' or the imagined hoped-for child (Teel, 1991; Lindgren, Burke, Hainsworth and Eakes, 1992).

There is also the underlying assumption that parents will need to adapt to their child's disability (Sloper and Turner, 1993; Alston and McCowan, 1995 and Bennett, DeLuca and Allen, 1996) across the life cycle as well as the need to develop instruments to measure the impact of disability on the lives of children and their families (Mackie, Jessen and Jarvis, 1998).

Moreover, rather than adaptation to a child's disability, it has been suggested that a parent's role and interaction are of particular importance in the type and nature of development of a child with a disability (Trevarthen and Burford, 1995; Buchan, Clemerson and Davis, 1987) with parental perspectives of a disability impacting upon the resultant needs of a child (Kalucy, Bower and Stanley, 1996; King, Rosenbaum and King, 1996). However, it is not always the perspective of parents that has been the focus of enquiry through the family unit. Craft, Lakin, Oppliger, Clancy and Vanderlinden, (1990) suggest that areas such as stimulation, interaction, competition and approval or disapproval could be influenced by siblings acting as agents of change. It has also been suggested that the social status of a family can impact upon the level of

home care for children with disabilities (Cohen, 1999) although earlier research suggests that a family unit with a disabled child does not necessarily mean that they are prone in any way to being dysfunctional and indeed (Spaulding and Morgan, 1986) found no distinguishing psychological characteristics to suggest to possibility of dysfunction.

These then are the issues of childhood disability in general which occupy the attention of the research community. More specifically, attempts have also been made to investigate programmes of Conductive Education through the perceptions of parents and these studies have focussed on the effectiveness of this system of education (Cooper, 1986; Sigafoos et al, 1991; Read, 1992; Hill, 1990; Mackenzie et al, 1991 and Read, 1995) and the appropriateness of investigating the effectiveness of a programme of Conductive Education is discussed in detail in Chapter two.

No research has been identified which looks beyond the effectiveness of programmes of Conductive Education to consider the issues which have actually contributed to the decision-making of parents - how the choice of education for their child is made and how they make sense of Conductive Education as a choice. However, recommendations have been made for future research to consider all aspects of service users' perspectives on Conductive Education (Read, 1995).

This research represents a collaboration between The National Institute for Conductive Education and The University of Wolverhampton to investigate the perceptions of parents who chose a programme of Conductive Education for their children with cerebral palsy.

1.2 Overall Aims of the Investigation

As already stated, attempts so far to discover why parents choose Conductive Education have concentrated on investigating the effectiveness of the programme of education. The implication of measuring effectiveness and/or satisfaction could suggest the expectation of a causal link between high levels of the measures and the choices that parents have made. In other words, finding a high level of effectiveness and/or satisfaction with a programme of education **after** enrolment could offer an explanation for parents choosing Conductive Education. However, such investigations restrict the findings to a particular point (or points if longitudinal) in time so that any causal links between measures and reasons for choosing are, in a sense, links of a retrospective nature. This investigation aims to engage with the context and uses of meaning that emerge from the data and which are related to parents' retrospective experiences (rather than researcher's retrospective links), current experiences and future expectations.

The overall aims of this investigation are

- The identification of parents' experiences and perceptions of the decision-making process.
- How parents make sense of their decision-making process.
- How parents and LEAs construct their versions of events related to the decision-making process and why they are constructed as they are.

The overall aim of this investigation is to address the shortfall in childhood disability research which arises from omitting to consider the experiences of parents prior to enrolment in a programme of Conductive Education. Central to this aim will be the exploration of parents' past and present belief systems, their understanding of local,

national and global perceptions of disability as well as their future expectations of a programme of Conductive Education for their child with cerebral palsy .

The focus of the existing literature has been upon evaluation of conducting as an educational and health intervention. This approach has only indirect implications for attempts to resolve the interesting question as to why parents expend so much effort in trying to access this form of education for their child. An understanding of the phenomenon will serve to illuminate the process by which families make sense of disability and its role in their lives.

1.3 Setting the scene

A background of related issues of a general nature was approached through investigation of the history of Conductive Education and its transportation to the UK, childhood disability, cerebral palsy, special education provision and legislation, the philosophy of education, current models of disability and past and current methodologies.

The specific background issues setting the scene for this investigation arise from three questions - what is cerebral palsy? what is Conductive Education? and how do parents access a programme of Conductive Education?

1.3.1 What is cerebral palsy?

Cerebral palsy is a motor disorder caused by a non-progressive abnormality of the brain. Non-progressive in this sense denotes a disorder that does not worsen over time. In terms of severity, it is possible for one child to have severe physical disabilities and no

non-motoric difficulties, such as hearing or visual impairment, whilst another child may have mild physical disabilities but have severe visual or hearing impairments; the term cerebral palsy covers a wide range of disabilities. It has been suggested that cerebral palsy is often characterised by severe physical disabilities, differing levels of intellectual development and functional skills (Bochner et al, 1996) and that the child with cerebral palsy will require specialised care (Rang and Wright, 1989). Read (1995) describes cerebral palsy as a condition where disease or damage to the central nervous system affects individuals' abilities to control bodily movement.

1.3.2 What is Conductive Education?

Conductive Education is an educational approach based upon a cognitive model that regards mental structures and potentials to be the products of pedagogic interactions rather than their determinants (Sutton, 1996). Conductive Education operates from an understanding that human learning is not biologically determined but instead develops actively. A unified approach (Taylor and Emery, 1995) with the main aim to create active, independent learners (Coles and Zsargo, 1998).

Sutton (1996) suggests that many of the basic principles of Conductive Education are linked with the work of Vygotsky (1960) and Luria (1961). Central to this link is the concept that a motor disorder such as cerebral palsy prevents an individual from developing a relationship to the world and, subsequently, a relationship with people. For Luriya and Vygotsky this lack of development could be overcome through appropriate social interactions which would result in higher-order cognitive functions compensating for lower-order damage to the brain. For Sukhmolinskii the central concept is concerned with a learner's experience of success which in itself raises a

paradox because in order for a learner to experience success the learner must be successful. Sukhmolinskii and Sutton address this paradox by including an element within a programme of education which enables the learner to experience success from the act of trying thereby creating the desire to learn. However, to understand the fundamental underpinnings of Conductive Education it is necessary to look at the developmental background of Conductive Education.

Before 1987 anyone interested in Conductive Education had to visit the Peto Institute in Hungary. Starting in 1987 Conductive Education was transferred to this country initially through a four year programme for British school teachers. The organisation that originated this transfer was the Foundation for Conductive Education in Birmingham. Andrew Sutton, the founding director, initially worked to transfer this system in as 'Hungarian' a way as possible, but had also recognised from the outset that Conductive Education could not be fully established in this country without adaptations to meet the needs of a different social, cultural and economic environment. So Conductive Education as it is practised at the collaborating Institute has been developed over 13 years to represent a new synthesis. In other words, the system emerging at the National Institute maintains the core affective approach central to Conductive Education but applied in a manner consistent with contemporary British values by linking the cognitive, motoric, emotional and social elements of individual activity and learning by the creation of meaningful and significant conditions to enable the child to learn (Read, 1998). The National Institute is subsidised by charitable funding with the bulk of its income coming from fees.

Conductive Education has been described as a system of habilitation, special education and rehabilitation for children and adults with motor disorders (Read, 1994). For children with cerebral palsy, Conductive Education provides a non-traditional, alternative programme of education. For children of pre-nursery age Conductive Education offers habilitational and educational services where children and their prime care-givers form small groups to learn jointly how to establish and maintain the ordinary mechanisms of adult-child reciprocal interaction. At nursery and primary-school age, children are helped in groups and the objective of the teaching throughout is to impart means to compensate for motor difficulties. The means by which the objectives are achieved are the establishment of higher personal goals and motivations which confirm the desire to move independently, linked with the experience of success as a result of making children's endeavours satisfying and rewarding (Sutton, 1996). In other words, children on a programme of Conductive Education experience success because their goal is achievable, they are motivated towards their next goal because of this experience of success and their desire to perform tasks independently, they move towards their next achievable goal and again experience success. These are the general fundamental precepts of Conductive Education which vary according to the needs of each individual child.

1.3.3 Parents' access to a programme of Conductive Education

Decisions on schooling are based upon a statementing process which is intended to lead to provision of resources and/or treatment. For example, a statement of a child's special needs is prepared by an LEA based upon parental, educational, medical, psychological and social services advice. The statement includes the name of the school which an LEA consider appropriate to meet the needs of a child. Whilst many changes in

legislation have taken place since the last major review of the educational needs of children in 1978 (the Warnock Report), parents who choose not to educate their disabled child in either mainstream or county special schools are required to justify their choice to the LEA who "are under no obligation to contribute towards the cost of educating the child at the school of the parents' choice." (Code of Practice (1994) section 4:64). Parents are required to provide reasons why they choose a programme of education other than that available through their LEA.

Of the theories that have been put forward to account for the educational choices made by parents of disabled children, it has been suggested, for example, that parents focus on a particular issue, such as education, using this as an anchor into which they pour their energies (Bax, 1993); or that they are in search of a miracle or a 'cure' when they move outside the existing structure (Oliver, 1989); that parents would naturally choose a system of education that was more difficult to obtain has also been suggested (Bax, 1993) and these theories will be explored in chapter five.

1.4 Importance of Study

Research which can offer an insight into why parents chose Conductive Education is of interest to all those involved in the education of children with cerebral palsy but of particular value to parents, educators and the service providers of education services.

This study offers the parents who were respondents, as service users of Conductive Education, an opportunity to step outside any boundaries imposed by questionnaires to tell their story in full, as they see it. The techniques of restriction associated with the use of questionnaires and identified by Potter & Wetherell (1987) are considered

inappropriate for this study for two main reasons. Firstly because the positivistic nature of seeking answers to pre-defined questions is suggestive of an expectation of truth-finding. In other words, the questions asked are considered by the quantitative researcher to represent a selective amount of information (related to the perceptions of parents on Conductive Education) which will offer an insight into parents' decision-making process. In this sense, the questions considered by the quantitative researcher to be appropriate will uncover the reasons for the decision and the questions themselves will represent an expectation on behalf of the researcher. As a consequence, the body of knowledge in this field would not be enhanced by a positivistic approach. "Science tells us what we can know, but what we can know is very little, and if we forget how much we cannot know we become insensitive to many things of very great importance." (Bertrand Russell, 1945. p. xiv).

This study, therefore, seeks to explore what we have not hitherto known by allowing parents the freedom of an unrestricted telling of their story.

The second reason for not adopting a positivistic approach to enquiry is related to context and this is a somewhat complex issue, but perhaps more so with regard to its relevance to this study. The complexity of this study arises from the fact that the socio-historical context of Conductive Education has, until the present time, been in a communist setting. Attempts to develop and discover a theoretical base for Conductive Education, as well as to address issues of effectiveness related to Conductive Education, as practised at the National Institute in Birmingham, have been based on its similarity (or not) to Hungarian practice. For example the Bairstow, Cochrane and Hur (1993) investigation, whilst allowing for the different socio-economic contexts of U.K. and

Hungary, nevertheless sought evidence of the effectiveness of Conductive Education at the National Institute and its degree of fidelity to the Hungarian model. The problems with such evaluation are two-fold. Firstly, the social systems in which Conductive Education is embedded are ignored. Secondly, the assumption is made that the model is not open to development but rather remains static over culture and over time.

This study must therefore consider Conductive Education as a programme of education that has evolved to meet the needs of a socio-historical context. The 'context' for this study not only represents the already-existing traditional programmes of education but also the expectations of parents such as the participants of the study. To this end, parents' past belief systems, current experiences and future expectations are examined to provide a socio-historical perspective on Conductive Education. This analysis will not be based upon the degree of similarities with, or fidelity to, the educational programme practised in Hungary.

The shift in the basic assumptions upon which investigations in this field have, to date, been based will offer a different view on how to theorise educational provision for children with cerebral palsy.

1.5 Limitations of the study

Two limitations of the study have been identified. The first concerns the size of the population for investigation (parents from approx. 11 family units). This limitation is addressed through the adoption of an appropriate methodology designed to explore the experiences of parents, as service users, in depth.

It has been argued (McCracken, 1988) that the first principle of qualitative research of this nature is that "less is more" where it is important to work longer and with greater depth with a few people than to work superficially with many. The study was designed to offer a picture of the complicated character, organisation and logic of the culture of parents as service users at The National Institute of Conductive Education. Whilst the primary aim is not concerned with how widely the findings are applicable to all parents of children with cerebral palsy, substantive, first-order grounded theory developing into higher-order general grounded theory offers the opportunity for generalisations to be made.

The second limitation of the study is that the perspectives of parents will be gained at one given point in time although their reflections and expectations will also form a major part of the analysis of data. This limitation will be addressed through the recommendation that childhood disability is never viewed as a fixed entity but that children are seen as active agents in their own development (Llewellyn & Owens, 1997).

Due to the interpretative nature of the methodologies applied to this investigation the findings are representative of *one* interpretation of what is happening and this important point becomes transparent through the identification and application of the methodologies in Chapters two, three, four, five and six.

Chapter Two: The Problem Conceptualised: the development of the framework

This chapter explores critical approaches to the concept of childhood, disability and education. Past and current research and theorising surrounding these areas are discussed in general and as they relate specifically to Conductive Education.

2.1 Introduction

The critical theoretical approaches to childhood, disability and education such as those adopted by Rose (1989a, 1989b, 1998), Gergen (1993), Burman (1994), Valentine (1992), Heather (1976) and Foucault (1977) form the basis of a conceptual framework for this investigation. These approaches have questioned the appropriateness of the application of mainstream psychological theory to issues of childhood, disability and education. Such critical analysis embraces the concept that all enquiry should be historically and socially context-driven. This thesis will apply a socio-historical analysis to the issues of childhood, disability and education and extend such analysis by consideration of these issues as they relate specifically to Conductive Education and therefore also, children with cerebral palsy.

It appears that for critical psychologists the basic assumptions upon which much of mainstream psychology is underpinned are not as tenable as once thought. The major problem arises through what psychology, as a science, determines represents a universal truth in the positivist-empiricist style of the discipline. A form of enquiry and representation that is universalising and decontextualised and consequently ignores the social process which, according to Gergen (1985), are endemic to an understanding of knowledge. From this perspective there is no ultimate, universal truth that can be uncovered through scientific enquiry – there are only versions of events which are

constructed both historically and contextually through social interaction (Foucault, 1977). Linked with Foucauldian thought is the notion that the social regulation of children is contributed to by psychologists for reasons that are not transparent but are in accordance with the economic and political demands of government (Billington, 1996).

Critical analysis applied to this investigation suggests that Conductive Education, through the perceptions of parents, cannot be understood here in the U.K., in the present time, by looking at how it has been practised in Hungary for the last 50 years. The particular questions which a critical theoretical approach poses for this investigation are related to the social construction of childhood compounded by the social construction of disability and education.

2.2. The Social Construction of childhood, disability and education

The concept put forward by Rose (1989b) with regard to childhood (if it is accepted as a distinct stage of the life-span) is that childhood is the most intensively governed sector of personal existence. There are measurements in place throughout childhood which both construct and inform this stage (Burman, 1994). This could be said to be especially the case for children with disabilities who, from the time of diagnosis, are monitored for purposes of health care, support and education. However, it has been argued that it is not always the child's welfare that is the target for particular agencies but the agencies' procedures themselves (Billington, 1996). In other words, the 'child' is a product of the agency of investigation.

Able-bodied children are primarily monitored through agencies of health and education and this is also the case for children with disabilities. However, the tools of

measurement are often of a normative style whereby children with disabilities are measured for limitations – what they cannot do in relation to what their able-bodied peers can do. Issues such as the importance of positive versus negative attitudes to education are known to be important (Drench, 1994) and have been hitherto ignored by the quantitative approach of investigating Conductive Education that is in the literature.

This quantitative approach to 'measuring' children does not only create a 'normalising' effect, but also suggests the existence of a supreme objectivity and truth. An understanding of how these issues have been researched and theorised in the past illustrates this point further. Moreover, this type of 'normalising' surveillance is not only carried out by government agencies but is also present in the family unit when 'expert' opinion is viewed by parents as representing an unquestionable truth. "The soul of the young citizen has become the object of government through expertise." (Rose, 1989b, p. 131).

2.3 The decontextualisation of childhood disability

Research into childhood disability in general has often been driven by a conceptual model of cause and effect (Heather, 1976; Llewellyn and Hogan, 2000) whereby the effect of a disability on an individual or a family is linked into the cause – the disability itself. For example, Bax (1998) suggests that the effect on parents of having a disabled child is that they experience unresolved bereavement which in turn causes the further effect of parents 'grasping at straws'. It has also been suggested that parents may experience chronic sorrow, anger and/or feelings of guilt (the effect) when a child with a disability resides within the family unit (the cause) (Lindgren, 1992; Bruce & Schultz, 1994).

Billington (1996) suggests that special education provision in an educational sense is self-serving - the educational systems have already been constructed and children are assessed to determine how they best fit into the structure. Further evidence on this point of view is provided by Wright & Poynter (1996) who maintain that special education provision is required to be 'adequate' not 'best'.

Interestingly, also, is the concept that LEAs are "under no obligation to contribute towards the cost of educating the child at the school of the parents' choice (Code of Practice, 1994; p. 94, section 4:64) but at the same time maintain that a partnership in the decision-making process exists between parents and LEAs.

2.4 The decontextualisation of Conductive Education

A similar, positivistic approach has been applied to research whereby programmes of Conductive Education have been evaluated for their effectiveness (Weber & Rochel, 1992; Dowrick, 1993; Hass et al, 1997; Darom, 1997 and Ornoy, 1997). For example, a positivistic approach to enquiry has also been extended to investigations where parental perspectives or perceptions of Conductive Education have been included to determine parental satisfaction with, or perceptions of levels of effectiveness of, short-term programmes in Australia (Cooper, 1986; Sigafoos et al, 1991), Hungarian programmes (Read, 1992; Hill, 1990; Mackenzie, Booth and Ritchie, 1991) and short-term programmes in the United Kingdom (Lie & Holmes, 1996). It has also been suggested that parents are unable to make choices with regard to their child's educational options because to them "all geese are swans" (Hall & Hill, 1996).

Although positivistic approaches to research and theory in this area are similar for enquiries both inside and outside the U.K., the national response in each case is very different. Many countries appear to have welcomed not only research but also the practice of Conductive Education as a system of educating children with cerebral palsy (Lebeer, 1995; Weber, 1995; Dowrick, 1993; Bochner et al, 1996 and Hass et al, 1997).

Of the further attempts to evaluate programmes of Conductive Education (Weber & Rochel, 1992; Dowrick, 1993; Hass et al, 1997; Darom, 1997 and Ornoy, 1997), the Weber & Rocher (1992) German clinical trial found that "every child demonstrated detectable dynamic development which was manifested in significant progress in physical, perceptual, cognitive, independence and social ability" (p. 242). Conclusions drawn were that Conductive Education should be incorporated into the system of special education in Germany. These results, based on slight evidence, contributed to the acceptance of Conductive Education as a system of education for children with cerebral palsy in Germany.

Acceptance of Conductive Education in the U.K. by agencies involved, however, appears to be hinged upon the identification of the theoretical basis of Conductive Education and proof of its 'superior' effects in comparison to traditional, existing programmes of special education. It appears that the positivistic approach to enquiry which is implicit through the reliance on the medical model of disability (Llewellyn & Hogan, 2000) is dominant in this field.

Even proponents of Conductive Education, for example Dowrick (1994), have suggested that the lack of a theoretical definition of Conductive Education has been

considered, at least partially, to account for a limited literature base. Paradoxically perhaps, an increased awareness outside the U.K., as well as emerging training schemes in the U.K., appear to be responsible for the current national interest in rather than a scientific evaluation of Conductive Education (Sutton, 1998).

Conductive Education as it is developing at the collaborating Institute (National Institute for Conductive Education) has, however, facilitated identification of common ground between Conductive Education and Luria's neuropsychology, Vygotsky's developmental psychology and Makarenko's pedagogy (Sutton, 1986b). Identification of a theoretical basis would be welcomed in the U.K. as a spring board for further research in this country (Sutton, 1996) rather than as evidence of effectiveness based on scientific evaluation.

2.5 Deconstruction of the definitive statement on Conductive Education in the U.K.

The mostly cited and discussed evaluation to date – the Bairstow, Cochrane & Hur (1993) Report - has a particular relevance to the present study and this is two-fold. Firstly, because the 1993 investigation was carried out at the collaborating Institute and secondly because the findings of the report rapidly assumed the status of the definitive statement on Conductive Education (Llewellyn, Owens & Hogan, 1997). Beginning in 1987, this U.K. government-funded report attempted, over a 5-year period, to measure the 'success' of Conductive Education at the Birmingham Institute in comparison with existing special needs provision in Manchester. The findings from a battery of tests led the authors of the report to conclude that "parents of children with cerebral palsy should regard with caution promises made on behalf of Conductive Education and they should

not feel they are failing if they do not secure Conductive Education for their child"(p. 197).

The study set out to look for "superior benefits" of Conductive Education from within the medical paradigm of existing approaches and with reference to traditional programmes of education. By adopting this approach the assumption was made that the 'treatment' aspect of LEA provision such as occupational therapy and/or physiotherapy could be compared alongside a programme of education (Conductive Education). When comparisons of education rather than treatment were considered, these were based upon the national curriculum with the further assumption that this would offer the educational focus for purposes of evaluation.

Just as importantly, Bairstow et al refer to Conductive Education as having 'failed', by doing so implied that 'norms' of conductive education in the U.K. had already been established. Hence the development of provision in Britain was ignored and indeed future progress hampered by their 'definitive' evaluation study.

Following on from its publication, the report received much criticism regarding its design and methodology. For instance, Stukat (1995) highlights the problems in attempting to match children with differing levels of disability and suggests that the negative terms in which the findings are expressed should be viewed with caution. Catonese (1995) offers many criticisms of the Bairstow et al (1993) Report. The first is concerned with the concept of orthofunction – "...a brilliant innovation given to describe the dynamic state between mind and body – put simply to possess the desire to act upon the world despite the physical limitations that are associated with neurological

damage. (p. 45). For Catonese, the Bairstow Report represents a failure to appreciate (or actively ignores) the psycho-social aspects of Conductive Education because the authors base their understanding of orthofunction on a biological framework of cerebral palsy. However, Catonese, whilst questioning the overall scientific credibility of the study, cites specific examples such as the sudden reduction (with no explanation) in the size of the sample group; a significant difference in the ages between the cohorts; and the control group (Manchester children enrolled on a programme of traditional special education) consisting of children with less severe physical disabilities than children in the Birmingham group. The recommendation made by Catonese is that future research in Conductive Education should attempt to avoid evaluation that is set in a narrow experimental or political framework.

As a result of the present critical evaluation a further, major issue began to emerge which has not, so far, been addressed. Since 1993 and up to and including 1997 the same authors of the Report (variously) published selections of the report and offered interpretations of the same data. The assumptions about childhood disability upon which the authors based these subsequent articles could be misleading for the research community. The main reason for this concerns the timing of the Bairstow, Cochrane and Hur (1993) original investigation which was undertaken between 1987 and 1993 and the timing of the publications following the report (Bairstow & Cochrane, 1993; Hur & Cochrane, 1995a; Hur & Cochrane, 1995b and Hur, 1997). It could be argued for instance that data collected in 1987 and submitted to the research community in 1997 are derived from the view that childhood disability, the education programme which is the subject of the research and indeed disabled children, have remained constant over time.

Although the limited lifespan of the research was recognised by Bairstow et al, themselves in 1993 – "statements relating to conductive education made in the present [1993] report pertain to conditions prevailing in the Peto and Birmingham Institutes over the period of this study, and may not be accurate or relevant in the future." (Bairstow, Cochrane & Hur, 1993 p.6). The fact remains that Bairstow & Cochrane, Hur & Cochrane, Hur & Cochrane again and Hur have continued to publish results from this study long after that date.

The latest publication (Hur, 1997) also moves the argument away from the relevance of the material to the possibility of misleading the research community. It refers to "the research design employed in the **present** study" and the title of the article is "a comparative longitudinal study". One might infer that the article is current (at the time of publication), that the data and findings are relevant to Conductive Education and, more particularly, to Conductive Education in operation in 1997 at the National Institute. The evidence that the research community is indeed drawing this inference concerning new data can be found in Hornby, Atkinson and Howard (1997). In evaluating studies carried out into Conductive Education in the U.K. Hornby et al report the findings of Bairstow et al (1993) in one paragraph which is followed by "In **another** study, Hur & Cochrane (1995) compared the differences in academic performance of children at the Birmingham Institute with children undertaking special education programmes in the Greater Manchester area..." (p.115). This clearly implies that Hur & Cochrane (1995) is viewed by Honby et al as a separate study to that of Bairstow et al (1993). That both studies have the same children as participants and use the same data is clearly misunderstood by Hornby et al (1997). By offering pictures of the original data as though they were based on new data the research community is holding itself

open to a charge of misleading those who look to it for authoritative information in guiding policy.

Other major implications of the Bairstow Report and its target of searching for "better rates of progress than U.K. special education" (Bairstow et al, 1993 p. 48) will be discussed throughout the investigation. The relevance of the Bairstow et al Report as well as subsequent articles by the same authors to this investigation is two-fold. Firstly because it is widely held to be the most rigorous study in this subject area not only at the collaborating Institute but also in the U.K. Secondly, this was firmly based on the medical model currently characteristic of research to date. This sets aside the possibility of there being benefits of Conductive Education that fall outside of the medical model of disability. For example, the aspiration of Conductive Education to educate the whole child, integrating the physical and emotional well-being into the activity of education – an approach that stands in stark contrast to the Gestaltian approach of 'treating' with occupational therapy and physiotherapy and 'educating' through the national curriculum. Conductive Education either shows superior benefits with reference to traditional programmes of education or it has been deemed to have failed.

The primary aims of the Bairstow enquiry have been to lay bare the theoretical bases of Conductive Education and at the same time simplify the experimental setting so that unequivocal conclusions may be drawn (Heather, 1976). In this particular area of research, however, these two aims are incompatible. The reason for this is not so much to do with the aims themselves but rather the angle (or paradigm) from which they are approached.

The paradigmatic base from which the research aims are explored is that of traditional education which in turn means that there are boundaries imposed upon the enquiry – as evidenced by the comparison group. It is in this sense that the experimental setting is simplified and indeed the research questions reflect this – is Conductive Education superior to conventional therapy and education and if not it has failed. The question then arises as to whether it is possible to uncover the theoretical basis of a non-traditional programme of education from within the boundaries set by understanding traditional education. Although Bairstow et al (1993) attempt to do just that they are somewhat defeated by the lack of historical literature concerning Conductive Education.

Similarly, the concept that a programme of Conductive Education can be deconstructed in order to identify the separate elements and their theoretical bases has proved difficult. It was (and still is) more the case that the action and meaning of the philosophical underpinnings of Conductive Education rather than its theoretical basis (as provided by elements of Conductive Education) which concentrated the attention of Sutton and parents in the late 1980s. However, Sutton (1998) identified a necessity for a theoretical component to be made explicit in order that the existing tensions between tradition on the one hand and economic and micro-political forces on the other hand might be addressed.

In this sense there were several levels of particular contexts with regard to Conductive Education operating in the U.K. which could not be examined through the limitations of a positivist model of enquiry adopted by Bairstow et al (1993). The levels themselves are both micro and macro – the context of the individual and Conductive

Education, the family and Conductive Education, the education system and Conductive Education and the U.K.'s socio-economic context.

2.6 Models of disability

The possible influential nature of current models of disability on parental choice is also central to the investigation of the perspectives of parents on Conductive Education. An illustration of the importance of this issue is gained from a review of the Bairstow et al (1993) report by a paediatrician and editor of a major journal on physical disability who suggests that "some parents present (who had been at the Birmingham Institute) strongly felt that the method *had* benefited their child, and it is always puzzling for parents as to why we professionals do not take their word for this." (Bax, 1993 p. 659). In short, the absence of data from formal objective tests to demonstrate the impact of Conductive Education means that parents are deluded. One might argue that it is surprising that in the face of parents' claims of progress and benefit, professionals continue to deny such benefits. Benefits such as moral, personal and physical growth do not form a part of a positivistic model of enquiry.

There is little doubt that the model of disability in this connection is strictly medical. The issues related to ownership, power, as well as the patronising nature of the discourse warrant full discussion and are taken up through the application of Discourse Analysis in Chapter Six.

The debates surrounding models of disability are related to the disadvantages experienced by disabled people and represent two main concepts – the medical model of disability and the social model of disability. The medical model of disability locates

disability within the individual so that a person's disability is the direct cause of any lost opportunities. The social model on the other hand views any disadvantages as stemming from society's inability or refusal to provide the services necessary for a disabled person not to experience disadvantage.

The appearance of the social model of disability is primarily as a result of dissatisfaction with the medical model (Read, 1998). The intrinsic nature and fundamental concepts of the medical model had been (and are) seen by academics in the disabled people's movement as actually contributing to the oppression inherent in the disadvantaged world of disabled people (Oliver, 1990; French, 1994 a,b). In this sense, the medical model encompasses therapeutic and rehabilitation services for disabled people with the aim being one of 'normalisation' such that disabled people must be helped to change to become as similar as possible to their able-bodied counterparts. The medical model of disability appears to view the disabled individual as out-of-step with the rest of the world – a sort of non-conforming person who must be changed, although this view has met with some resistance (Morris, 1991; Hevey, 1992).

The extrinsic model on the other hand, the social model, promotes the concept of societal influence being responsible for the experience of disadvantage whilst at the same time not ignoring the existence of impairment (Oliver, 1990; Morris, 1991). In this sense it is society's failure to adequately support disabled people which is the cause of disadvantage (Oliver, 1996).

A more complex but somewhat contradictory view on models of disability is put forward by Oliver (1996). From Oliver's perspective (an adult who became disabled as

an adolescent) the individual model or 'personal tragedy theory' of disability is not acceptable and neither is the medical model. The contradictions contained in Oliver's writing (1989, 1996) arise with regard to Conductive Education, not necessarily because of the views expressed on the medical model of disability but, more simply, because of a paradigm confusion. Oliver sees the medical model as oppressive and extends the argument to Conductive Education, seeing similarities between this system of education and Hitler's "vision of normality associated with blond hair and blue eyes" (Oliver, 1989, p.200) But Oliver's understanding of Conductive Education is linked to the main concepts of the medical model of disability whereby all forms of rehabilitation or therapy are oppressive because of their 'normalising' characteristic. But this notion could demonstrate a cursory knowledge of Conductive Education. If Conductive Education were purely a system of rehabilitation or therapy then the links to the medical model would be obvious. However, Conductive Education is a system of education and yet Oliver argues *for* the empowerment of disabled people but *against* Conductive Education on the assumption that Conductive Education is a therapy and not a system of education.

Whilst Oliver dissects the inadequacy of current approaches to disability it has been suggested by Beardshaw (1989) that there is no basis for the argument that service users of Conductive Education are straw clutchers.

Whether a more recent model of disability – the social model - offers a full account of disability is still being debated (Bury, 1996; Williams, 1996). Read (1998) however warns against assuming "a focus entirely on external structures.....appear[ing] oversimplistic and reductionist" (p.288).

2.7 Summary

Critical theoretical approaches to childhood, disability and education have been discussed. Deconstruction of the 'definitive' statement on Conductive Education highlights the inadequacy of evaluation based on a positivistic, medical model of disability. Such an approach views Conductive Education as a system made up of separate elements which address the needs of a child, such as physical and emotional needs, separately and, as such, the aspiration of Conductive Education to integrate the whole child through the activity of education is ignored. Although an educational focus has also been present during evaluation this has concentrated on the national curriculum and is representative of an individual part of a traditional programme of special education. Therefore the positivistic education model of disability also operates on an understanding that Conductive Education can be separated into elements for the purposes of evaluation. The dissimilarity in the philosophical underpinnings of Conductive Education and a traditional programme of special education suggest that comparisons are neither possible nor fruitful in gaining an understanding of either programme.

To this end, the aims of this study will shift enquiry from parents' perceptions of the effectiveness or satisfaction with Conductive Education to consider their perceptions on a programme of education that has evolved to meet the needs of a socio-historical context offering a different view on how to theorise educational provision for children with cerebral palsy.

Chapter three: Towards an appropriate methodology

This Chapter sets out the route to the identification of a combination of methodologies (the strategy) before their specific nature (the tactics) is identified in Chapters Four, Five and Six.

3.1 The Strategy

In the vein of Manstead & Semin's (1988) river-crossing analogy, the starting point in the search for an appropriate methodology or combination of methodologies is to consider how many people want to cross the river, the frequency with which they want to cross, the current of the river, how people have crossed this river in the past, how much luggage they will take with them on the crossing and why they want to cross in the first place.

In selecting an appropriate methodology or combination of methodologies for the investigation of parents' perceptions of Conductive Education three major factors were identified as contributing to the process – the basic requirements of the research question(s); the total population and subsequent sample size; indications from past methodologies in this field.

These factors are discussed separately and the conclusions drawn together to identify an appropriate strategy for this investigation, beginning with the first of these three factors:

3.2 The basic requirements of the research question(s)

This investigation aims to discover parental perceptions of Conductive Education and how parents make sense of the decision-making process which leads to their final choice of an appropriate programme of education for their child with cerebral palsy. There are two main parts to the research question. The first element of enquiry is *exploratory* - the identification of parental perceptions on Conductive Education. The second element of enquiry is both e*xplanatory* and *descriptive* - how do parents make sense of this decision-making process in which they are involved. The initial investigation uncovers what is happening in this population i.e. the phenomenon under investigation and the issues surrounding the phenomenon both temporally (past belief systems, perceptions of disability and future expectations) and determinantly (social support systems, perceptions of disability, personal knowledge-base). The second element of enquiry, explanatory and descriptive, identifies causal relationships between the phenomenon (why did this occur) as well as the conditions or context of the occurrence (in what setting does the event happen). For example, a certain event, X, occurs because of the cause, Y, under specific conditions or in the context of, Z. The requirements of these two elements of enquiry differ considerably.

The exploratory nature of the enquiry should be as flexible as possible to facilitate the emergence of, as yet unknown, phenomena as well as the gentle moulding of the adopted strategy to accommodate new avenues of enquiry if they should arise as the investigation progresses.

Conversely, the explanatory nature of enquiry requires as much structure as possible in order to validate relationships and temporal processes within the data.

The essence of the basic requirements of the research question is taken forward when considering the second major contributing factor in the identification of an appropriate strategy.

3.3 The total population and subsequent sample size

To all intents and purposes, due to the collaborative nature of the investigation (parents as service-users at the National Institute of Conductive Education), the participants are a captive population. In other words, the participants are from an already existing group rather than a random selection of a population. The size of the population is identified as parents from 21 family units (family units being a family system of either one parent with or without siblings or two parents either with or without siblings). Early request for participation in the study resulted in the sample size of parents from 11 family units (the exact details of the identification of participants appear in Chapter Four).

This sample size suggested that exploration of the topic should, of necessity, be in-depth. In this sense, the sample size would reflect the notion already discussed that 'less is more' (McCracken, 1988) whereby a smaller number of participants whose experiences are investigated in detail is likely to be more appropriate for this study than a larger number of participants being investigated in a superficial or pre-structured manner as with questionnaires. The reason for this, apart from the sample size, is that the investigation does not begin with exacting, pre-conceived ideas of what is being investigated. Therefore the focus of investigation will only become transparent through in-depth exploration of issues involved.

The implications gathered from consideration of the first two contributing factors, the basic requirements of the research question and the sample size, are taken forward to consider the third major contributing factor:

3.4 Indications from past methodologies

As discussed in the previous chapter (Chapter Two), past methodologies in this field have usually been designed to evaluate the effectiveness of Conductive Education as a programme of education and/or parents' level of satisfaction with this system (Cooper, 1986; Sigafoos et al, 1991; Read, 1992; Hill, 1990; Mackenzie et al, 1991; Read, 1995 and Bairstow et al, 1993). Research designed to evaluate Conductive Education has used a combination of methods including quantitative and qualitative approaches. Although qualitative methods of enquiry have rarely had a place in this field, nevertheless the approach has been driven by the medical model of disability.

This research is raising a question outside the medical model and hence the choice of methods will necessarily reflect a different emphasis of the choice of methodologies made. As the research question for this thesis will arise out of the concerns for these parents without setting out with pre-existing ideas on what is to be found (Bairstow et al, 1993; Lindgren, 1992; Bruce & Schultz, 1994; Weber & Rochel, 1992 and Hass et al, 1997) the quantitative approach of hypothesis testing cannot be followed.

This investigation aims actively to discover the phenomenon *through* the collection of data, without the testing of pre-existing theories. In other words, past methodologies have focused on an event or issue (e.g. parents' level of satisfaction) and have aimed to test that event or issue through the use of a methodology which uses hypotheses as its

starting point or through the descriptive interpretation of structured or semi-structured data collection.

This investigation aims to look beyond parental perceptions of the effectiveness of Conductive Education or their level of satisfaction to consider the issues which have actually contributed to the decision-making process of parents and how they make sense of this process. The phenomenon under investigation was not therefore identified until after the investigation began.

The exploration of these three major contributing factors, and their implications, led to the final selection of an appropriate strategy for this investigation. These implications are now drawn together and the methodologies identified.

3.5 Identification of the strategy

The conclusions drawn from consideration of the three major contributing factors are that an appropriate methodology or combination of methodologies should include elements that will offer:

- unstructured, in-depth exploration
- identification of the phenomenon
- opportunism
- description and structured context-related explanation

Based on the above criteria, quantitative methods of enquiry were considered not best suited to accommodate the flexibility of the first element of enquiry - the exploration.

Similarly, the second element of enquiry - explanation and description - would not benefit from the adoption of a quantitative method, due mainly to the sample size. However, the main reason for not adopting a quantitative approach arises from the positivistic nature of enquiry inherent in such methods as has been discussed through the identification of a conceptual framework in Chapter Two.

The choice of a qualitative approach raised three central issues - whether the data are to be reduced and described? whether the data are to be analysed or reported as collected? whether the data are to be used as a tool for building theory?

The terms upon which an appropriate qualitative methodology should be chosen are the same as the terms upon which the decision between a quantitative or qualitative methodology were made i.e. the requirements of the research question, the implications drawn from investigation of past methodologies in this field and the number of participants.

Whereas during the consideration of a quantitative methodological approach the number of participants was felt to be inappropriate (parents from 11 families), in the qualitative realm the number of participants in terms of in-depth data collection can be considered to be quite high. In other words the sample size would represent intensive enquiry rather than extensive investigation as suggested by McCracken (1988).

The central issues above suggested the need for the data to be reduced to emerging themes for the purpose of the identification of parental perceptions. Description alone, however, was not considered appropriate to uncover how parents make sense of the

decision-making process. A structured analytic approach was considered to be most suited for this purpose and also in organising the data thematically. The third issue considered central to the identification of an appropriate qualitative methodology was whether the data were to be used as a tool for building theory. As the investigation does not begin with a hypothesis, extensive exploration of the data would be necessary to identify 'what is going on'. This process of exploration could be put to further use by choosing to build the theory from the ground up because familiarity with the data, along with structured coding procedures, would serve to ground emerging theory by validating it with the, by that stage, familiar data.

3.6 Summary

In summary, a qualitative method needs to incorporate a methodology with sufficient structure to organise the reduced data as well as the facility to enable the identification of causal and contextual relationships within the data.

For this reason, as well as to validate the emerging theories through the strength of structure of the analysis, Grounded Theory (Strauss & Corbin, 1990) was chosen as one of the most appropriate qualitative methodologies with which to proceed. The exact nature of the application of the major elements of Grounded Theory are set out in the next chapters– Chapter Four and Five.

3.7 Towards a combination of methodologies

Whilst the methodology of Grounded Theory in itself is ideally suited to exploring the issues which contribute to the decision-making process of parents and the modification of existing theories (and generation of new theories), this methodology was not

expected to enable engagement with *meaning* or exploration of *how* the events and incidents were constructed. These were considered to be vital components for theoretical development to take place.

The adoption of the Grounded Theory method of enquiry does not represent the whole picture of the strategy for this investigation, although it is through the use of this methodology that an additional avenue of enquiry is identified.

During the data collection stage of the enquiry (which is fully described in the following chapter - Chapter Four) an opportunistic product of grounded theory emerged when an unexpected element of data in the form of documentation became available. This documentation represented an interaction between two parties involved in the decision-making process. The relevance and importance of the unexpected data to this investigation arises because the two parties are not in agreement on the choice of educational programme considered to be appropriate for a child resulting in the documentation being related to two **opposing** parties.

The opposing nature of the discourse contained in this documentation is examined through the use of Discourse Analysis (Potter & Wetherell, 1994), to uncover in what way each party has constructed their version of events and, just as importantly, why these events are constructed as they are. In other words, each party offers a claim to truth about an event or incident - how has each version of events been constructed by each party. In order to address issues related to the paradox of writer-construction a further technique is incorporated into the analysis and discussion through discourse analysis. Inherent in the application of discourse analysis is the possibility of the writer

creating a further construction of events through the words chosen to report them. To this end, the technique of parallel reflexivity (Mulkay, 1985; Ashmore, 1985) is adopted to reduce, if not eliminate, this possibility.

3.8 A meeting of methods

The two methodologies adopted represent different yet complementary elements of enquiry. This complementary element is clarified by Richardson (1996) who suggests that grounded theory aims for coherence in its final account whereas discourse analysis, for all intents and purposes, undermines coherence by promoting distrust through constant deconstruction of accounts. The distrust is represented by the concept that each account offers only one version of events rather than an ultimate 'truth'. The triangulation of enquiry occurs when the findings and discussions from the two methodologies are brought together in an overall discussion to form a third angle of enquiry.

In essence, grounded theory is applied to interview data to identify the central issues surrounding parents' perceptions on a programme of Conductive Education and, in so doing, may also offer suggestions for the modification or support of existing theories. It is, however, also possible to take the research question one step further by approaching the central issues from a different angle. This situation primarily arises because Conductive Education is not a part of LEA provision and LEAs seldom agree with the choice that parents make and, more often than not, resist requests for funding. The impact that this situation has on the findings through the application of grounded theory is such that whilst the primary aim is to identify the central issues involved, it is also possible to identify the major discourses in action. This arises because whilst parents

are offering their perceptions on Conductive Education they are also making comparisons with other options available to them as well as highlighting issues related to their enrolment on a programme of Conductive Education. Therefore, whilst the application of grounded theory serves to identify the central issues related to parents' perceptions on a programme of Conductive Education – explicitly, familiarity with the data also serves to identify the discourses involved in the decision-making process – implicitly.

With regard to grounded theory for instance, the basic assumption is that there are themes and concepts that 'exist' and that through the application of grounded theory, these will be identified. This in turn is suggestive of a notion that the researcher's interaction with participants does not in any way serve to bring about a particular construction of events – the events already exist and await identification. However, this notion of an existing reality is addressed through the approach adopted and becomes transparent as the investigation unfolds. It is also addressed or complemented through the use of discourse analysis whereby the basic assumption about the language used is that there is no one 'real' meaning but instead a multipe set of meanings that are context driven. In this sense the notion of reality is one where it is obscured and through an analysis of the discourses involved a meaning for the construction of the discourses will emerge.

In order to further explore the discourses which are in operation in the repertoires of parents, the research question is taken one step further through the application of the second methodology, discourse analysis, to the discourse used by the decision-makers.

The exact nature of the application of each of the methodologies is set out separately in Chapter four and Chapter six.

These two angles of enquiry are drawn together to form a triangulation of enquiry as a means of finding out where something is by getting a 'fix' on it from two different places (Robson, 1993 p. 290) and this represents the final discussion of the findings from both methodologies.

3.9 Summary

In summary, this chapter identified the major factors contributing to the selection of an appropriate methodology or combination of methodologies (the strategy). Discussion of these major factors results in the adoption of a combination of methodologies for this investigation, namely Grounded Theory (Strauss & Corbin, 1990) and Discourse Analysis (Potter & Wetherell, 1994) with the findings from each of these methods being drawn together to form a triangulation of enquiry (Robson, 1993).

3.10 The Structure of the thesis

The thesis is structured around two areas of enquiry. In Chapters Four and Five the Grounded Theory method of enquiry is applied to data which represent the perceptions of parents on Conductive Education. The exact nature of enquiry is set out through the initial coding procedures of Grounded Theory and a theoretical framework is developed. For purposes of clarity and continuity the reporting of the analytical story occurs alongside the discussion. A summary discussion serves to highlight the emerging theoretical implications.

Chapter Six sets out the application of Discourse Analysis to documentation related to parental decision-making. The analysis is reported alongside the discussion and is supplemented by the application of parallel reflexivity which serves as a technique of instantaneous clarity of issues which could arise as a result of the discourse used in reporting. An overall discussion draws together the emerging theoretical implications.

Chapter Seven draws together the theoretical implications from each methodology and highlights the extent to which the research questions have been addressed. The study, as a whole, is considered in a reflexive manner and addresses the exclusion of data through illustrative examples.

Chapter four: The Tactics Identified - Grounded Theory Applied

This chapter sets out the specific nature of enquiry through the application of the initial coding procedures of Grounded Theory. The aim of the chapter is to set the scene for the development of the theoretical framework and the reporting of the analytical story in Chapter five.

4.1 The Conceptual framework of Grounded Theory

Disagreement between the originators of the grounded theory approach – Glaser & Strauss (1967) – on matters of procedure have lead to speculation as to the 'right' way to apply this methodology (Rennie, 1998a, 1998b; Corbin, 1998). However the main aim of this methodology has not changed over the last thirty years i.e. "to develop a well integrated set of concepts that provide a thorough theoretical explanation of social phenomena under study" (Corbin, 1998: p.5).

A component of grounded theory which is held to be of great importance is that of change. In order that the area under investigation is not seen as static, an element of 'process' is built into the approach whereby it is possible to see changes in the type of action taken, according to the nature of the conditions. This element of process becomes transparent for this investigation through the variation identified in the data as well as the temporal processes which emerge.

However, the extent to which the procedures of grounded theory are applied is a flexible matter resolved by the needs of the research question although it has been suggested

that following the procedures with care will result in an element of rigor being built into the investigation (Corbin, 1998).

Historically, the theoretical underpinnings of the major elements of grounded theory are sometimes held to stem from pragmatism (Dewey, 1925; Mead, 1934) and symbolic interactionism (Park & Burgess, 1921; Thomas & Snaniecki, 1981; Hughes, 1971; Blumer, 1969). However, it is not necessary to reach agreement, on either the accuracy or the appropriateness, of these theoretical links prior to the application of the coding procedures of Grounded Theory. It is possible, as Corbin (1998) suggests, to view any links more as a background knowledge rather than as a compliance with the assumptions represented by such links.

Nevertheless, it is important to indicate that the extent to which the techniques of grounded theory are applied will determine whether the outcome will be one of description or explanation. Whilst the identification of themes or concepts in the data would offer research findings of the event or problem under investigation, (sections 4.3 to 4.3.4), it is only through the statements of relationship than an explanation, a theory, will emerge (Strauss and Corbin, 1998). The exact nature of the building of relational links, and hence theory, are set out from section 4.3.5 to section 5.10 in chapter five.

However, notwithstanding the importance of building the procedures, identified above, into the approach, it is important that these procedures are made explicit if the approach is to be effective. Examination of all possible angles provided by the procedures leads to a theory being grounded in reality (Glaser & Strauss, 1967).

that following the procedures with care will result in an element of rigor being built into the investigation (Corbin, 1998).

Historically, the theoretical underpinnings of the major elements of grounded theory are sometimes held to stem from pragmatism (Dewey, 1925; Mead, 1934) and symbolic interactionism (Park & Burgess, 1921; Thomas & Snaniecki, 1981; Hughes, 1971; Blumer, 1969). However, it is not necessary to reach agreement, on either the accuracy or the appropriateness, of these theoretical links prior to the application of the coding procedures of Grounded Theory. It is possible, as Corbin (1998) suggests, to view any links more as a background knowledge rather than as a compliance with the assumptions represented by such links.

Nevertheless, it is important to indicate that the extent to which the techniques of grounded theory are applied will determine whether the outcome will be one of description or explanation. Whilst the identification of themes or concepts in the data would offer research findings of the event or problem under investigation, (sections 4.3 to 4.3.4), it is only through the statements of relationship than an explanation, a theory, will emerge (Strauss and Corbin, 1998). The exact nature of the building of relational links, and hence theory, are set out from section 4.3.5 to section 5.10 in chapter five.

However, notwithstanding the importance of building the procedures, identified above, into the approach, it is important that these procedures are made explicit if the approach is to be effective. Examination of all possible angles provided by the procedures leads to a theory being grounded in reality (Glaser & Strauss, 1967).

4.2 Towards the development of a theoretical framework

4.2.1 Identification of Participants

Participants were identified through a letter of request for participation in the research (Appendix I). Total population of service-users in the nursery and school groups at the collaborating Institute (National Institute of Conductive Education) comprised parents from 21 family units.[1]

Agreement to participate was received from parents of:

6 family units having children with cerebral palsy enrolled in the nursery group.

7 family units having children with cerebral palsy enrolled in the school group at the collaborating Institute.

Parents from two family units in the school group were subsequently unable to participate due to extended illness in one family unit and personal difficulties in another. Parents from the 11 family units were contacted by telephone to make arrangements for informal, unstructured, in-depth interviews to take place at their convenience.

Ever mindful that it is the events or incidents emerging from the data rather than the participants themselves which were the subject of the investigation it is, nevertheless, useful to include the make-up of the family units with regard to the number of parents in each unit and whether or not each child with cerebral palsy had siblings. This breakdown is intended to give the background of the families in the study.

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[1] Family 'units' representing a family system which could be made up of either two parents (mother and father) or one parent (mother or father). For this investigation family units with one parent refers to a mother.

Family Unit	Number of Siblings
With two parents - 9	7
With one parent - 2	1

The parents are from a wide range of socio-economic backgrounds. Pre-determined categories were not used, the information is based on researcher observation and interpretation. This information is intended as just that - information – a background that indicates that the data collected from participants is not representative of any specific socio-economic group of parents.

With regard to those parents who decided not to take part in the investigation, enquiries carried out at the collaborating Institute were not suggestive of this group of parents representing a coolective reason for non-participation other than constraints on their time. Similarly, the participants of the investigation also expressed contraints on their time and, although clearly interested in participation would do so through one interview situation.

4.2.2 The formation of interview questions

The two main sources for the formation of interview prompts were identified as:-

- review of existing literature
- observation

Existing literature was reviewed on two separate occasions during the course of the investigation. Firstly, before the interview process began, in order to gain a background to the field and to aid in the formation of interview prompts and, secondly, during the final stages of analysis and in light of the emerging theories. For the purposes of the

formation of interview prompts the first literature review revealed two broad based topic areas -

General - Childhood disability in general and surrounding issues

Specific - Conductive Education and children with cerebral palsy

The issues which relate specifically to Conductive Education and children with cerebral palsy are easily identifiable. However, those issues related to childhood disability in general need further clarification for their relevance to become transparent. Issues from existing literature on childhood disability in general, whilst not dealing specifically with Conductive Education, are nevertheless related to the perceptions of parents on Conductive Education. An example which illustrates this is found in Bax (1998) where it is suggested that because parents do not have the 'normal' child they had hoped for they are suffering a form of extended bereavement and are subsequently more likely to grasp at straws because they have either lost the ability to be objective or never possessed it in the first place. The usefulness of including a concept, such as the inability of parents to be objective, as an item for exploration with parents, lies in the possibility of discovering the existence (or not) of relationships between parents' non-acceptance of their child's disability/limitations/reality and their choice of educational programme. Similarly, all of the issues which arose from the first review of existing literature in relation to childhood disability in general, and which are set out in chapter two, were deemed worthy of exploration with parents.

The second source from which the formulation of prompts emerged was from observation. Attendance as observer at two parent-led discussion groups at the collaborating Institute built upon ideas gained from examination of existing literature.

Notes were taken on issues discussed and emerging themes were:-

- parents as experts
- enforced battle for enrolment in a programme of Conductive Education
- accessibility of Conductive Education

A tentative list of prompts began to form which encompassed the issues from the two sources discussed above. However, an opportunistic product of grounded theory, which is discussed next, led to an understanding of the applicability of prompts for this investigation.

During observation at parent-led discussion groups the first opportunistic product of the application of grounded theory emerged. In their capacity as past service-users at the National Institute of Conductive Education four members of a family (mother, father, adolescent child with cerebral palsy and sibling) agreed to participate in the investigation to

- test the appropriateness of prompts emerging from existing literature and observation;
- generate new prompts.

All family members agreed to take part in informal, unstructured, in-depth, tape-recorded interviews. The extent of their experience included:

- service users of Conductive Education as practised in Hungary;
- service-users of Conductive Education as practised at the collaborating Institute
- service-users of education as practised in mainstream schooling

- service-users of education as practised in special educational provision

This valuable source of data served as the starting point from which the investigation proper could proceed and also served to clarify the applicability of the prompts which had begun to form.

4.2.3 Applicability of interview prompts

During the first interview (family unit and past service-users of Conductive Education) it became immediately apparent that the issues which had emerged from the review of literature and observation at parent-led meetings, were all issues which arose, spontaneously, as members of the family unit began their story. It was also apparent that, during an investigation where the aim was to identify hitherto unknown phenomena, it would be inappropriate to use questions for any purpose other than to validate data from future interviews against data from earlier interviews.

In essence, asking participants the same question would not aid the process of finding out what was going on. However once a theme was identified, from one or several interviews, the focus and content of a future interview could be steered toward issues of enquiry (if the themes were not covered by the participants spontaneously).

The issues emerging from the first literature review and observation at parent-led meetings were viewed as an exercise in obtaining background information to take to the interviews as a knowledge base rather than information on which to base interview prompts.

4.2.4 Procedure for interviews

Location and duration of interviews were entirely parent-led. Parents were interviewed in their homes, in a local park or in a quiet area of a café. Unstructured, in-depth, tape-recorded interviews lasted between an hour and two-and-a-half hours. Prompts based on theoretical samplings, observation and data from the family unit as past service-users of Conductive Education were seldom necessary as participants' story-telling techniques addressed most, if not all, issues related to the research question. Participants were asked to "tell your story as you see it" and the prompts were used when necessary. Parents covered relevant issues spontaneously (and usually chronologically), beginning and ending their stories at their discretion.

At the beginning of each interview the researcher thanked parents for offering to participate in the investigation and described the nature of the research – a collaboration between the University of Wolverhampton and The National Institute for Conductive Education in Birmingham. An indication of the general aims of the investigation were described by the researcher as an attempt to determine the perceptions of parents on a programme of Conductive Education and, as such, parents could start their stories at a point which they perceived to be the beginning. However, although parents were not asked a set of questions, inherent in each interview process was the researcher's knowledge of possible issues surrounding parents' perceptions on a programme of Conduction Education and therefore parents were often requested to elaborate further on particular points.

Participants were advised that they could end the interview at any point and could withdraw from the investigation if they so wished. On several occasions during

interviews, incidents naturally occurred which served as ice-breakers and these are illustrated and discussed in chapter seven.

At the end of each interview parents were given the opportunity to reflect on their repertoires and at this time parents sought confirmation of confidentiality of the information provided. Also at this time, parents were asked whether they would be agreeable to telephone contact by the researcher if , during the process of transcription, it appeared that there were points raised that subsequently needed further clarification or elaboration. All participants agreed to this mode of contact and this useful element of supplementary enquiry (Strauss and Corbin, 1998) was utilised on two occasions.

4.2.5 Ethical Issues

The participants of this study represent parents who have enrolled their children on a programme of Conductive Education at The National Institute for Conductive Education in Birmingham and their choice has often resulted in confrontations with their LEA through disagreement. As such, although prepared (and often eager) to tell their stories parents were aware that, because of their particular circumstances, it would be inappropriate for the transcripts of their interviews to be made available. Also, as parents have to rely, periodically, on their LEAs assessment of their child's progress on a programme of Conductive Education as the criteria for funding to continue, concerns were expressed about the confidentiality of the interview material. As the data were to be analysed through an in-depth application of the coding procedures of the grounded theory method of enquiry with many of the techniques utilised as representations of the data, participants were assured of confidentiality with any quotations being of a generic nature in order to preserve anonymity.

The presence of the researcher, however was a key factor in the accounts that emerged and illustrations of this aspect appear in Chapter seven. The participants' perception of researcher was likely to be one of difference (attached to a university and a collaborating institute, mid- forties, parent of able-bodied children) but this did not appear to be the case. Possibly because of the unstructured nature or the location of the interviews, as well as the incidents that occurred (discussed in chapter seven), participants told their stories in full, sometimes with the caveat that this would not have been the case if the information were not to be dealt with in a confidential manner. It would appear then that the decision to collect the data in full knowledge of how it may not be used was taken by balancing the other option – the full use of superficial data. In this respect, the researcher takes the responsible position of reporting on the issues involved and the (almost technical) use of the grounded theory of methodology came into play.

4.3 Coding procedures for grounded theory applied

4.3.1 Rationale

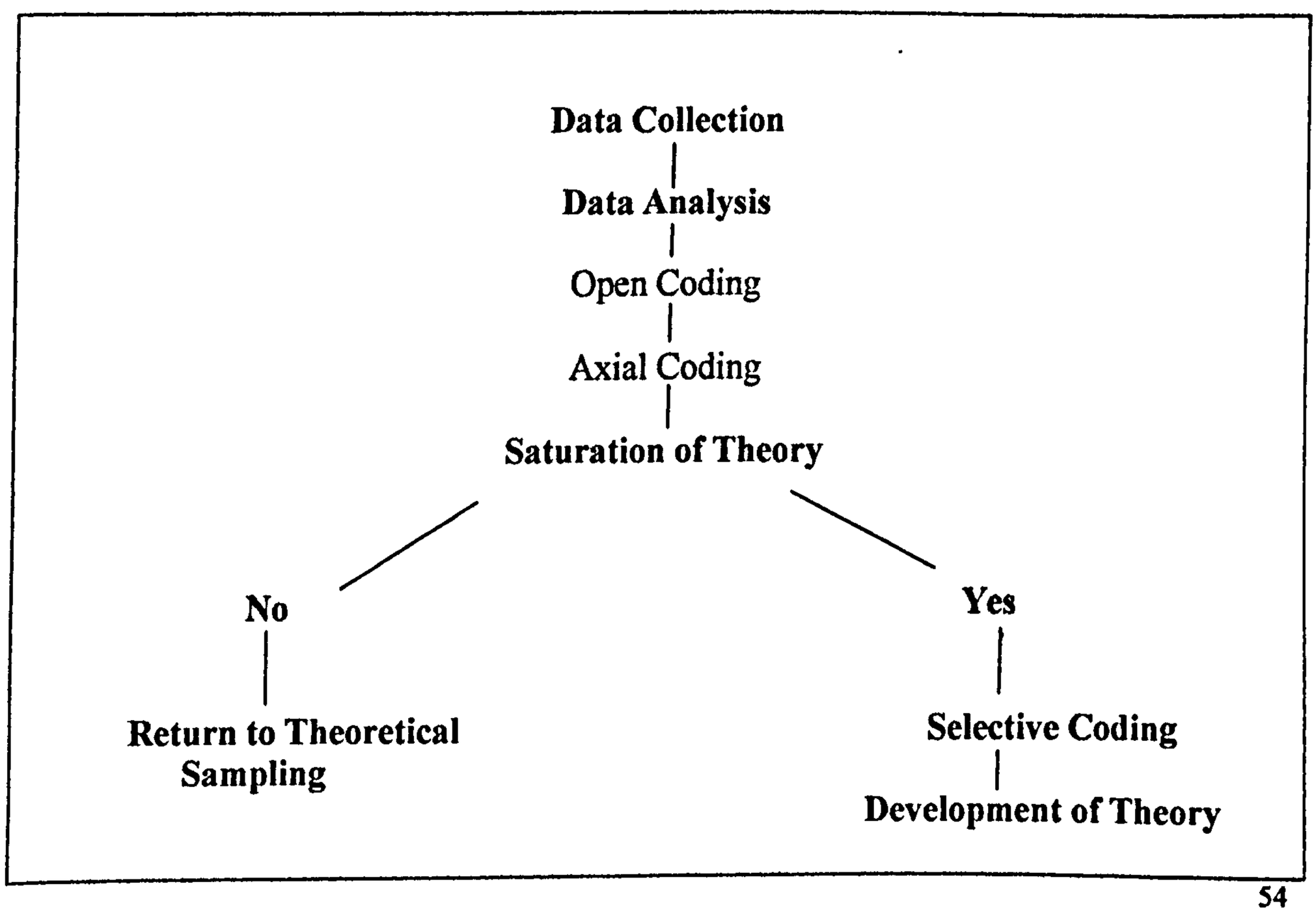
Grounded Theory lends itself to customisation in the sense that as much (or as little) of the coding procedures can be applied according to the needs of the investigation. For the purposes of clarity in the application of Grounded Theory the extent to which the coding procedures is applied forms the specific tactical base from which the theoretical developments emerge in Chapter Five.

Illustration of the variation in the data, which is an essential part of the grounded theory method, occurs almost naturally in this investigation in the sense that no additional analysis is necessary for them to emerge. This is due mainly to the fact that the stories of parents include not only their perceptions on Conductive Education but also their

perceptions on what, to them, is their alternative choice - a traditional programme of special education. As a result of this factor, some of the conditions reported on will refer not only to those under which the phenomenon exists but will also include the conditions under which, for some parents, the phenomenon does not exist i.e. is not necessary. This is the variation in the data which is intended to strengthen the emerging theoretical implications through the specific conditions under which the phenomenon exists.

Many of the stages of the grounded theory method of enquiry are approached simultaneously with data collection directions for one set of data being dependent upon what was found in the previous data collection. Although not discrete stages, a broad framework, based on suggestions by Pandit (1996), is set out in figure .1.

Figure .1. Framework of coding procedures



The purpose of each of these procedures together with their results are set out under separate headings, however, the first stage of the framework, data collection, needs no clarification as it has already been set out through the procedures identified.

The second stage, data analysis, requires detailed definitions.

4.3.2 Data Analysis

Two coding procedures are initially applied to the data:

- open coding
- axial coding

These two coding procedures serve different analytical purposes but both move the data one step further towards the development of theory. The basic procedure for each are set out as follows:

4.3.3 Open Coding

The data from each interview were transcribed from tape-recordings as soon as possible following its collection. Subsequent data collection occurred in parallel with the data analysis of the previous collection of data. Each data set was allocated a number chronologically according to the order in which they were collected. Transcripts were numerically coded, with line numbers appearing in the right-hand margin of the transcripts every tenth line within each set of data. Examination of the data revealed concepts and these were labelled on the transcripts.

Conceptual labels, of events and incidents contained in the data, were allocated according to emerging concepts or ideas. Subsequent sets of data were examined for similarities to, as well as differences from, the previous data set, and allocated the same (or new) conceptual labels. The concepts identified throughout the data were:-

Academic independence

Acceptance of disability/reality

Acceptance of limitations

Belief Systems

Control

Current Disability

Definition of CE

Denial & False Hope

Economic

Emotional Issues

Mediated learning

Miracle Cure

Other providers of CE

Parents as experts

Passive vs active

Perceptions of disability

Perceptions of education

Personal independence

Physical independence

Positivity vs negativity

Potential ability

Problem-solving

Social support system

Trust erosion

Want/don't want

The data, which were coded by data set per family unit, were then taken apart and re-ordered by concept rather than by interview.

The data were coded, by concept, and numbered by line. For example, Past Belief Systems data set 1, lines 3-10 (data by concept) would appear in a separate list as ds1,3-10 (data by interview) in order that each incident of a concept could be traced

back to its source. In other words, each data set was separated conceptually and put back together again to form a new set of transcripts - transcripts by concepts.

When each concept became saturated i.e. nothing new could be learned from the collection of more data on a particular concept, relationships were sought between the concepts themselves. Related concepts were grouped together and allocated an abstract label to encompass them all and this group then became a category. Categories and sub-categories were identified as:-

Balance Options

Want/Don't want

Cognitive Facilitation

Mediated learning

Problem-solving

Evaluating

Miracle Cure

Definition of CE

Other providers of CE

Positivity vs Negativity

Identity Facilitation

Potential Ability

Current Disability

Independence

Physical

Academic

Personal

Other

Personal Context

Acceptance

Emotional

Denial & False Hope

Social Context

Perceptions of disability

Economic

Social Support Systems

Belief Systems

Perceptions of Education

Reclaim Ownership

Control

Parents as Experts

Passive vs Active

Trust Erosion

4.3.4 Axial Coding

The next step in the coding procedure formed the basis for development of relationships between categories and their sub-categories - axial coding. These categories are considered to be the central ideas in the data – the issues relevant to parents' perceptions of Conductive Education. Relationships in this instance represent a cluster of ideas with common themes linked together by the construction of an abstract label to encompass all of the themes of a particular category. The building of theory does not begin until the selective coding procedure as set out in the next section of this chapter – 4.3.5.

Properties and the dimensions of properties were developed. A simple, general application illustrates the grouping of concepts and identification of properties and dimensions.

CATEGORY (Abstract Label)	**Evaluating**
SUB-CATEGORIES	Miracle Cure
	Definition of C.E.

'Other' providers of C.E.

Balancing

As an illustration, the properties and dimensions of Miracle Cure were developed to:

Miracle Cure

Properties	Dimensions	
Acceptance of disability	partial	total
Acceptance of reality	partial	total
Acceptance of limitations	partial	total
False Hopes	early	late
Potential achievement	realistic	unrealistic

The properties and dimensions of properties contained in the data were identified for each category and, for the purposes of clarity in reporting the findings, these are laid out and discussed in full in Chapter five.

The main purpose of this particular coding procedure is as a stepping stone to the final application of the paradigm model which identified the central phenomenon. The relationships between categories and sub-categories, were identified through constant examination and re-examination of the data, as:

Independence *and* social support system

Independence *and* belief systems

Cognitive facilitation *and* peer group dynamics

Cognitive facilitation *and* physical independence

Cognitive facilitation *and* academic independence

Current disability *and* trust erosion

Current disability *and* acceptance

Potential ability *and* current disability

Potential ability *and* independence

Potential ability *and* cognitive facilitation

Evaluating influences *and* perceptions of disability

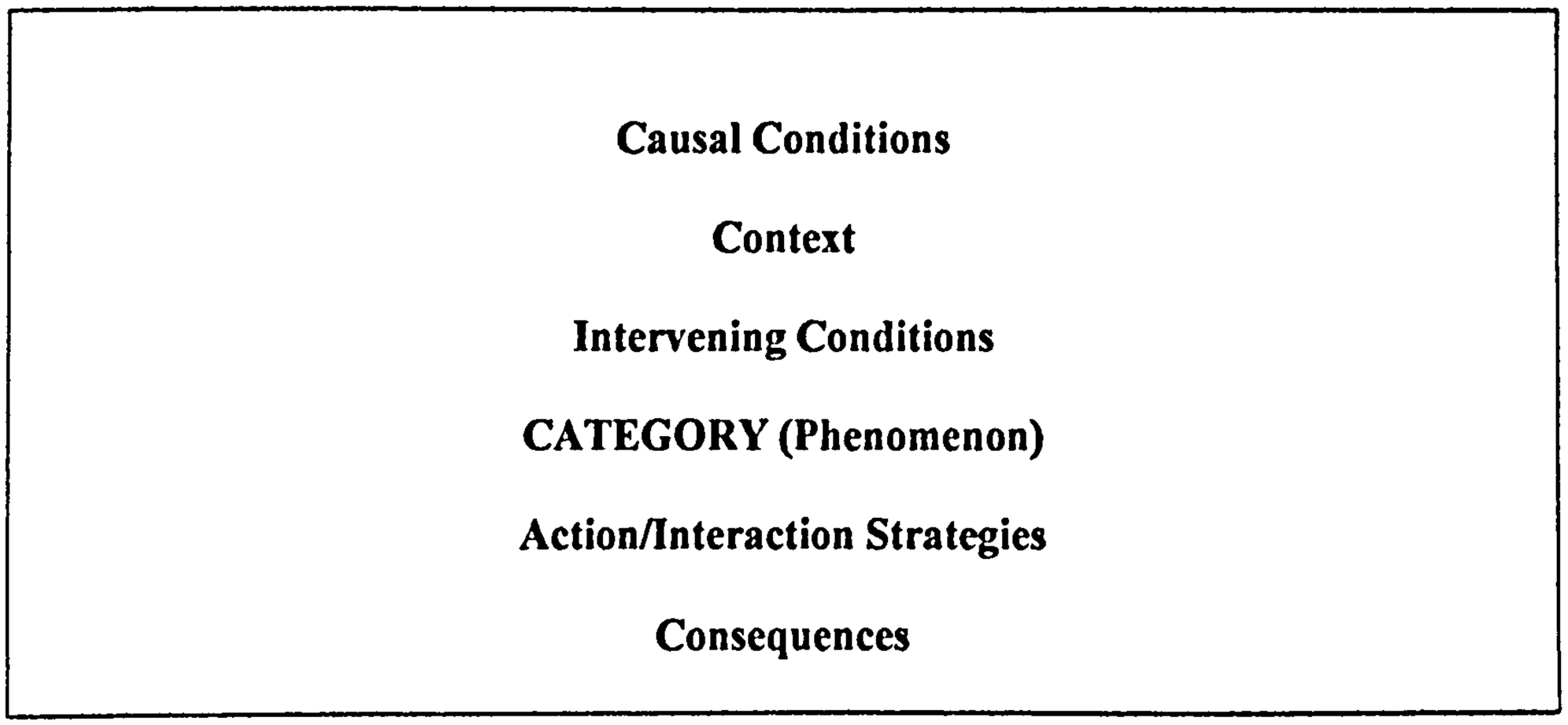
Evaluating educational options *and* perceptions of education

Balancing options *and* emotional issues

4.3.5 Selective coding

The application of the paradigm model (Strauss & Corbin, 1990; Pandit, 1996) was the point from which the framework began to emerge by developing relationships between the major categories. The paradigm model serves to identify the phenomenon or central story of the investigation through a framework that incorporates all of the major categories as related to the phenomenon. Identification of a phenomenon or core category is the point at which the power of the analysis changes from one of description to one of explanation. The core category will serve to identify the relationships between the major categories and the central story – the development of theory. The framework is:-

Figure .2. Framework of the paradigm model (Strauss & Corbin, 1990; Pandit, 1996)



The phenomenon is not an existing category to which sub-categories are related through conditions, context, action and consequences. The phenomenon is identified in three stages before being related to major categories:

- **identification of the story** which is central to the investigation. The story emerges through a narrative which encompasses ALL the major relevant issues which are deemed to be representative of the central story.
- **identification of the phenomenon** through the creation of an abstract label which best encompasses the whole story - the story line
- **development of a theoretical framework** through the application of the paradigm model.

4.3.5.1 Identification of the Story

The first step in this process identified the 'story' as follows:-

Generally speaking, the trajectory involved in parents choosing a programme of education for their children and their children enrolling on an educational programme could be expected to be somewhat linear except when the choices made by parents of children with cerebral palsy do not agree with the provision offered by their local education authority. Parents recognise this disparity as due to differences in the fundamental principles upon which education for children with disabilities is based.

Parents' trust

in expert opinion is eroded as they become researchers into educational provision and related issues. They perceive an active (as opposed to passive) education programme, beginning as early as possible in the life of their child, as being a major, positive contributing factor in the construction of their child's identity. Parents believe that a passive programme of education will have major, negative repercussions on the future identity of their child. Parents perceive an appropriate programme of education for their child to be based on the potential ability of that child and consider education programmes based on a child's current disability to be inappropriate. Parents feel themselves forced into reclaiming ownership of their child's education to ensure that the future identity of their child is potential-orientated.

This story was basically the researcher's interpretation of what was happening throughout all of the data and forms the basis from which the theoretical implications emerge. As such, the responsibility to 'get it right', fortunately, was not solely based upon one researcher's particular interpretation. The grounded theory method has, built into it, a process by which it can be determined at several stages whether the story is 'right'. This safety net process looks like this. The story was narrated and each concept was validated against the data to ascertain whether it was indeed what was going on. In this way, amendments were made as necessary until each concept in the story was

validated through the data. The 'rightness' of the story and the story line were also tested in the final stages of selective coding which was the next step - the identification of the story line.

However, this clarification is not intended to imply that another researcher could enter the investigation, look at the emerging relationships between categories and come up with the same story because of the safety net process of grounded theory (although this is entirely possible). The main reason for this is because the interviews were unstructured and deliberately so. The intention was to identify the central themes and, during the process, it was possible for each interview to differ in focus as well as content (Morse, 1997). Indeed, strict measures of inter-reliability could have resulted in the coding procedures being maintained at a superficial level as Morse has suggested - "perfectly reliable but trivial". (Morse, 1997 p. 447).

4.3.5.2 The basic assumptions underpinning the story are addressed

The basic assumptions underpinning the story were, of course, another matter and are best explained whilst the material is fresh in the reader's mind rather than being included in a chapter of reflexivity at the end of the analysis. For example 'an expected linear trajectory' cannot be passed over simply as one researcher's interpretation of the whole data which must be accepted by the reader. This clarification also serves to demonstrate the necessary flexibility of the grounded theory method because it is not only the analytical procedure that refines the emerging story. Indeed discussions with a colleague and mentor on the specific question of the possibility of a linear trajectory, representing choosing a programme of education and enrolling on that programme, serve to clarify this issue.

The discussions addressed the issue of whether a linear trajectory exists when childhood education is not complicated by childhood disability. If this were indeed the case, the statement contained in the story above is based upon a fundamental assumption – that childhood disability complicates an otherwise straightforward process. In other words, for parents with able-bodied children enrolment onto education programmes is plain-sailing - LEAs make offers and parents accept unquestioningly. However, this is not always the case. Parents of able-bodied children also evaluate their child's educational options and choose a system which they consider to be most appropriate for their child's education. The difference is that parents of children with cerebral palsy, who choose Conductive Education for their child, do not choose a different environment which operates on the same fundamental principles as all special schools, they choose an alternative, non-traditional programme of education. Conductive Education also has a national curriculum to follow and the Institute is also subjected to OFSTED inspections but the principles upon which conductive education operates are, fundamentally, very different (Read, 1998).

To summarise, parents who choose Conductive Education are not unusual in the sense that they don't agree with the provision offered by an LEA. They are unique in the fact that they choose a programme of education which is fundamentally dissimilar to that provided by LEAs. The reasons why parents do this emerge through the discussion of all the conditions under which the phenomenon exists.

A final point on the basic assumption of the possibility of a linear trajectory is that this was what was happening in this data i.e. the perceptions of parents as participants of this investigation suggest that a process which they perceive should be linear was, for them,

non-linear. In other words, the existence or not of a linear trajectory is outweighed by the fact that parents *perceive* the linear trajectory to exist. These implications are discussed through the relationships between categories at a property and dimensional level as the analytical story is reported and discussed.

4.3.5.3 Creation of Storyline

The second step in the process, the identification of the story line, revealed 'Orchestration of Identity' to be the central phenomenon or core category of the investigation.

At this stage the importance of the use of the paradigm model comes into effect when the major categories are related to the core category and grounded theory tests again the 'rightness' of the emerging story. The possibility existed that the major categories would not fit neatly into the paradigm model, strongly suggesting that the core category may have been wrongly identified as being the phenomenon that was central to the story. This not uncommon experience (Strauss & Corbin, 1990) results in the re-identification of the story line until all the major categories related neatly to the core category.

For this investigation the first core category to emerge and be tested was 'The Big Divide' which represented the difference between what parents perceived to be an appropriate system of education and current special educational provision. However, although several major categories could be related through their causal/contextual or action/interaction strategies and consequences through the paradigm model, not all

major categories fitted into the model. As a result of this some of the issues considered to be major factors in the story were not included.

The second attempt at identifying the core category – 'the orchestration of identity' – was successful because all of the major categories could be related (as conditions of the phenomenon) and included in the paradigm model.

The complexity of analysis through grounded theory warrants that the time when the analytic message starts to emerge through the process of selective coding is also the starting point from which the findings are reported. Also, because of the complexity, reporting the findings is also the point at which the discussion takes place so that the emerging theoretical implications are made transparent.

In other words, the reporting and the discussion of the findings occur at the same time in order to maintain the coherence of the emerging implications. A further important issue, related to reporting techniques, concerns the structured use of the grounded theory method of enquiry. The more common technique of providing evidence in support of findings is the incorporation of qualitative data into the report. For this investigation the structured use of the coding procedures facilitated an organisation of the data which represents the evidence of the findings – the properties and dimensions of each category. In this way the common themes as well as the variations in the data are illustrated through reference to the dimensions of the properties of each category.

The relevance of this technique for this investigation is not only related to the structured use of grounded theory but also to issues of anonymity. Parents who have

received funding from their LEA for enrolment at the Institute are subject to regular assessment by their LEA in order for funding to continue. Parents have told their stories on the understanding that their views will remain anonymous but because of the number of parents involved and because their stories represent a particular population in the area of special education it is possible that any discourse could highlight their identity. Therefore, the data used as illustrations in the reporting process are possibly generic in content whereas the data itself are abundant in specificity. However, the generic quotations are strengthened by the identification of the properties and dimensions of each category.

4.4 Summary

In summary, the application of the grounded theory method of enquiry is set out through the specific tactics of investigation. Findings from open coding and axial coding procedures set the scene for the identification of the story and the storyline. The final stage of the selective coding procedure – the development of a theoretical framework – forms the basis from which the analytical story and the theoretical implications emerge and are set out in Chapter five.

Chapter five: The implications emerge

This chapter unwraps the analytic message by laying out the theory which emerges through the reporting and discussion of the findings through the selective coding procedures of grounded theory.

5.1 The framework

The framework, set out on the next page, (Table .1.) is both the culmination of the many coding procedures of grounded theory and the starting point from which the analytical story begins. Within the theoretical framework are the conditions under which the phenomenon – the orchestration of identity – exists.

5.1.1 Analytical narrative of the framework

In the grounded theory style of 'what is happening here' an outline of the total analytical narrative of the theoretical framework is that *under conditions of childhood education complicated by childhood disability parents orchestrate the identity of their children. Parents control influences by means of evaluating the level of danger to their child's identity, balancing the options available to them, reclaiming ownership of their child's educational options and selecting Conductive Education. Influences perceived to be beneficial are enabled and the potential identity of their child is facilitated and on course.*

The analytical narrative (which appears in italics) is validated by testing all the components against the data as confirmation that this is a 'true' picture of what the researcher perceives is happening thereby grounding the emerging theoretical implications.

Table .1. Parents of Children with Cerebral Palsy: Their perspectives on Conductive Education as a choice of programme and how they make sense of the decision-making process

F R A M E W O R K

CAUSAL CONDITIONS
The interactive effects of childhood disability and childhood education

ACTION/INTERACTION
Reclaiming Ownership
Balance Options
Choose Conductive Education

PHENOMENON

ORCHESTRATION OF IDENTITY

Identity course
Perceived dangers to identity

CONTEXT
Properties of Core Category:
Identity Course
Perceived dangers to identity

INTERVENING CONDITIONS
between Context and Phenomenon
Evaluating Influences
Evaluating Educational Options

CONSEQUENCES
Identity on course

5.1.2 Structure of analysis

For the purposes of clarity each condition under which the phenomenon exists is reported individually using several techniques. The reporting begins with an analytical narrative of the specific conditions under which the phenomenon exists. The properties and dimensions of each condition are used to illustrate the conditions specifically as well as to report on the relationships between categories at a dimensional level. A second technique moves the reporting outside of the specific conditions to view them in light of the whole story of the data unrestricted by the properties and dimensions of each category. The manner in which these two techniques operate can be likened to a jigsaw puzzle whereby the pieces of jigsaw are the specific conditions of the phenomenon (the first technique) whilst the whole story is the cover picture of the finished jigsaw puzzle to which the analyst is privy (the second technique).

Reporting and discussion of the findings through the procedure of selective coding will cover the conditions set out in Table .1., namely:

- Causal conditions
- Context
- Intervening conditions
- Action/interaction strategies
- Consequences

The analytical narrative of the causal conditions of the orchestration of identity i.e. the events or incidents that lead to the existence of the phenomenon, forms the first piece of the jigsaw which is the analytical story.

5.2 Figure .3. The phenomenon and the causal conditions

PHENOMENON

Orchestration of Identity

CAUSAL CONDITIONS

Childhood education complicated by childhood disability

5.2.1 Analytical narrative of causal conditions

An analytical narrative of the theoretical framework identifies the causal conditions that *under conditions of childhood education complicated by childhood disability* parents orchestrate the identity of their children.

5.2.2 Report and discussion of phenomenon and causal conditions

The causal conditions under which the phenomenon exists are the interactive effects of childhood education and childhood disability. In other words, the phenomenon would not exist without these interactive effects. This interaction, as a cause of parents orchestrating the identity of their child, did not exist in this country with regard to long-term programmes of education for children with cerebral palsy prior to 1987. Conductive Education as it is currently understood had not been introduced into this country at that time. However, it is possible that this interaction existed with regard to short-term programmes of Conductive Education, practised in Hungary and available prior to 1987, although this is not the subject of investigation here. It is also possible that parents in general orchestrated the identity of their child before 1987 but not in respect of Conductive Education in this country.

The possibility of the existence of a linear trajectory was mentioned briefly in Chapter four. Its relevance here is that whether a linear trajectory exists (or not) is not the central issue. What is central is that a trajectory of enrolment existed for parents of children with cerebral palsy prior to 1987 which was different from the trajectory that exists post-1987 and that this has been recognised by the parents in this investigation.

Before the introduction of the core affective approach of Conductive Education (set out in Chapter One) to Birmingham in 1987 parental choice of a programme of education rested upon the provision offered by their LEA in the form of mainstream or special education. Under those circumstances a child with cerebral palsy would be assessed by their LEA and parents would be informed of the educational provision considered to be appropriate for their child. Parental choice prior to 1987 remained within the realm of traditional programmes of education provided by LEAs.

Since 1987, when Conductive Education was introduced to Birmingham parents who had heard of this alternative, non-traditional programme of education could, in theory, add this system to their choices. It is the very fact that it is only 'in theory' that parents add Conductive Education to their choice of programme that lies at the centre of the interaction between childhood education and childhood disability and the resulting non-linear trajectory of enrolment on a programme of education. This is because LEAs have not included Conductive Education as an optional programme of education for children with cerebral palsy. In practice the trajectory slips off the rails for two reasons. Firstly because parents' choice is outside the provision of special education by LEAs and hence is not automatically funded by LEAs and secondly because parents' preferences are held, by experts, to be ill-informed (Bax, 1993; 1998; Hall & Hill, 1996; Oliver, 1996)

and this second point is best explained through the application of discourse analysis in Chapter Six.

Both the inductive and deductive powers of grounded theory come into play in reporting this and many of the following issues. The inductive process of the possibility of a non-linear trajectory is discussed when the intervening condition of evaluation is reported. Deductively though it is reasonable to suggest two points with regard to parental choices. Firstly that if LEAs included a whole-system approach of Conductive Education in their choice of special education then the participants of this investigation would have a linear trajectory in terms of enrolment. Secondly, if 'expert' opinion suggested that a child would benefit best from a programme of Conductive Education then their LEA would consider the opinion to be informed (this point is extended further in Chapter Six).

Inductively, the data suggest that parents have themselves become experts on cerebral palsy and educational options. Although parents becoming experts is reported on and discussed fully under the action parents take to bring about the orchestration of their child's identity briefly it suggests that before parents reluctantly take on the role of experts they evaluate and balance the options open to them. In doing so they find, from several sources, that LEA provision needs to be 'adequate'. 'Adequate' is the nature of provision specified by LEAs (Wright & Poynter, 1996) and several parents have questioned this term with LEAs who have not voluntarily supported their choice of Conductive Education as a programme of education for their child. In answer to their question these parents have been told that LEAs are not required to provide the 'best' but 'adequate'. In terms of the choice that these parents have made – Conductive

Education – and the alternative choice which they have decided against – LEA provision – these parents have deduced that LEAs, by their own admission, believe their provision to be adequate and the parents' choice to be best. But it is the perceptions of parents that are under investigation here and not the perceptions of LEAs.

The second issue is concerned with parents' opinion on choices being considered by experts to be ill-informed. Existing literature suggests that parents' vast store of knowledge is widely ignored because their opinion would be hopelessly exaggerated and unreliable due to the fact that to them all geese are swans (Hall and Hill, 1996). If this were the case it would be reasonable to deduce that parents have not accepted the limitations or reality of their child's disability but the data for this investigation suggest otherwise and will be discussed in relation to the contextual conditions later in this chapter.

Specifically on the subject of parents' choices being ill-informed, Bax (1993) reported that "some parents....strongly felt that the method (Conductive Education) *had* benefited their child and it is always puzzling for parents as to why we professionals do not take their word for this" (p. 659).

One possibility is that whilst professionals are able to offer a general understanding of how to educate children with cerebral palsy the parents are able to offer an understanding of how to educate their individual child with whom they are the experts. So instead of assuming that the choices themselves are at fault (and subsequently the parents who make them) the method for understanding educational provision could be brought into question.

Parents who are the participants of this study perceive that LEA provision and Conductive Education are different on a fundamental level. It is the gap that exists between the two systems which parents see as creating the possibility of danger to the future identity of their child as evidenced by the contextual conditions of the phenomenon reported next.

The gap between what parents believe constitutes an appropriate programme of education for their child and what LEAs offer becomes apparent through the laying out of the context, intervening conditions, action and consequences of the phenomenon.

5.3 Figure .4. - The phenomenon and the context in which it exists

PHENOMENON

Orchestration of Identity

CONTEXTUAL CONDITIONS

Identity Course

Perceived dangers to Identity

The context in which the core category exists also represents the properties of the core category as already explained in Chapter Four. Therefore the perceived dangers to identity and the identity course are both the properties of the phenomenon and the context in which the orchestration of identity occurs. The level of perceived dangers to

identity (high to low) determines through the data whether the identity is on or off course.

5.3.1 Analytical narrative of contextual conditions

The theoretical development emerging from these two properties, through data validation, implies that *dangers to their child's future identity is perceived by parents to be of a high level, and the identity off course, if the fundamental underpinnings of the proposed programme of education is geared towards a child's current disability.* This statement sums up the theoretical implications with regard to the relationship between the phenomenon and the context in which the phenomenon occurs. Looking at their relationships in depth serves to lay out the theory from which the implications emerge.

5.3.2 Report and discussion of phenomenon and contextual conditions

To begin this part of the story, when parents perceive the identity of their child to be in danger, they take the step of orchestrating identity in order to avoid the future identity of their child being off course. The other pattern in the data is that parents perceive that the dangers to their child's identity are of a low level and the future identity of their child is on course.

Firstly it is appropriate to clarify at this stage exactly what is meant by the orchestration of identity. Johnston (1973) suggests that identity is what you can say you are according to what 'they' (in this sense, 'others') say you can be. Parents believe that their child's individuality and actual selfhood can be impacted upon by the type of educational programme they experience. They perceive that their child's identity is constructed. They also perceive that they have two courses open to them which will

have a bearing on their child's future identity. The first course is to choose a programme of education which will accommodate their child's disability and the second course is to choose a programme of education which caters for their child's potential ability. Both of these courses are seen by parents as resulting in completely different possible outcomes with regard to the future identity of their child. Perceiving this, parents decide to orchestrate or have a hand in the direction that the future identity of their child is to take and this process is reported and discussed through the properties and dimensions of the following contextual conditions.

Threats to their child's identity are best laid out through exploration of the properties of the phenomenon which are: -

- Independence
- Cognitive facilitation
- Disability
- Potential Ability

The analytical story of each of these categories is reported *in italics* and the theoretical implications discussed in terms of the broader picture through their relationships to other major categories.

5.3.3 Independence as a contextual condition

The properties and dimensions of independence illustrate the specific conditions under which the phenomenon exists, contextually:-

Table .2. Properties and dimensions of Independence

Properties	Dimensions	
Physical independence	Encouraged	not encouraged
Temporal	Early	late
Performance of tasks	Aided	unaided
Environment	Passive	active
Playtime	Passive	active
Verbal communication	Encouraged	not encouraged
Symbols	Encouraged	not encouraged
Perception of disability	Fixed	changing
Personal toileting	Facilitated	not facilitated
Eating	Passive	active
Drinking	Passive	active
Dressing	Passive	active
Success at task performance	Facilitated	not facilitated
Peer group dynamics	Present	absent
Self-confidence building	Facilitated	not facilitated

The context in which independence exists is seen by parents as representing two possibilities. The first possibility is that the dangers to identity are of a high level and their child's future identity is off course.

5.3.3.1 Analytical narrative of independence – first possibility

The analytical narrative of this possibility is that *under conditions where physical independence is not encouraged, either early or late in the trajectory; tasks are performed, aided, in a setting perceived to be passive; play time is addressed by means of child laying on floor (or equipment) with no stimulus; verbal communication is not encouraged but a system of symbols introduced to match a child's current disability; personal toileting, eating, drinking and dressing are not facilitated; success in performing tasks unaided either within the dynamics of a peer group or individually and self-confidence building is not facilitated* then parents perceive the identity of their child to be off course.

EXTRACT DS5:610

"...swimming all morning and relaxation and massage in the afternoon. So that's a day basically on a mat, waiting their turn."

EXTRACT DS6: 412

"He's not allowed to take his nappy off...they said that if they potty trained all the kids they'd never do anything else."

EXTRACT DS8:232

"What they wanted to do at ..... 'because his speech isn't very good we'll put him onto symbols." Oh God, yes, they were sending symbols home. I'm not going to even attempt....and he'd try and tell us what he wanted."

In summary, illustrations from the data serve to highlight parents' perceptions that the possibility exists whereby the level of dangers to their child's identity are of a high level, resulting in future identity being off course.

5.3.3.2 Analytical narrative of independence – second possibility

The second possibility is that parents perceive the dangers to their child's identity to be of a low level and their child's future identity on course. This analytical narrative says that *under conditions where physical independence is encouraged early in the trajectory and tasks are performed, unaided, in a setting perceived to be active; play time is addressed through enjoyment of tasks; verbal communication is encouraged; personal toileting, eating, drinking and dressing are facilitated enabling success in performing tasks, unaided, within the dynamics of a peer group and self-confidence is facilitated* then parents need take no action because the identity of their child is on course.

EXTRACT DS8:255

"Yes, he will get undressed himself and take his shoes off as well...he could never get the hang of taking his socks off but he does now."

EXTRACT DS8: 230

"We know it's doubtful he'll ever walk but what we are looking for is he can be independent."

EXTRACT DS9:302

"I think the biggest thing is the way C. is confident, she is very self-confident, she can adapt to I would say any situation. It's made her very confident in her abilities even though she knows the limit of her abilities she will have a go at absolutely anything."

EXTRACT DS10:408

"Well I think.....the different attitude to teaching children with disabilities. A lot of things would be done for her and to her and because they haven't got time to spend with the children they don't have the philosophy that Conductive Education has in letting the children try to reach the goals themselves."

As can be seen from the extract, in this scenario, parents perceive the dangers to their child's identity to be of a low level and the future identity to be on course.

5.3.3.3 Report and discussion of phenomenon and the contextual condition of independence

There are no degrees to the dimensions of the properties of independence. Parents perceive that an appropriate programme for their child should contain all of these elements totally (represented by the dimensions of Table .2. and validated through the data). However, if all of the data were the same then only one of the above conditions would be reported but a variation in the date necessitates the reporting of the second

condition. This second condition suggests that parents take no action because the identity of their child is on course. To clarify, this does not mean these (three) parents do not orchestrate the identity of their children but instead represents a variation in the conditions due to a temporal shift. This stems from a relationship between other properties for these three parents – their social support system and belief systems.

5.3.3.4 Social Support and Belief Systems

Table .3. Properties and dimensions of social support and belief systems

Properties	Dimensions	
Social support system		
Level of support - local	High	low
- personal	High	low
Past belief system		
Experience of special ed.	Present	absent
Experience of disability	Present	absent
Present belief system		
Trust in experts	In tact	eroded
Temporal	Early	late

These three parents, like the other participants, believe that all of the elements of independence influence the identity course of their children. The variation occurs because they have prior knowledge of educational options and had determined Conductive Education to be the most appropriate programme of education for their child prior to any evaluation process. Of these three parents two received support from their visiting physiotherapists with one parent also having experience of cerebral palsy and educational options in the past. These two parents did not enter into an evaluating or balancing process but had made their educational decision based on the knowledge already acquired. These two parents did not experience opposition from their LEA

when they chose Conductive Education for their children. The third parent had past and current experience of cerebral palsy and educational options and also did not need to evaluate or balance based on prior knowledge but did receive some opposition from the LEA resulting in a follow-through of the decision rather than the adoption of action based on knowledge recently acquired.

For the remainder of the parents two major temporal elements were recognised in relationships between categories:

- physical independence and academic ability
- physical independence and potential ability

5.3.3.5 Physical independence and academic ability - Analytical narrative of physical independence

An analytical narrative shows that *under conditions where parents perceive the identity of their child to be on course through the facilitation of physical independence parents begin to think specifically of their child's academic ability. However, if parents believe their child's identity to be on course but that their physical ability is not quite secure because they were unable to begin a programme of Conductive Education as early in the trajectory as they felt was appropriate then, they delay consideration of a child's academic ability.*

5.3.3.6 Report and discussion of physical independence and academic ability

There are two processes occurring here. Both are described succinctly by a parent as "physical first, Einstein second" meaning that parents do not give as much consideration

to their child's academic ability until they feel that their child's physical independence has been addressed.

EXTRACT DS6:474

"I don't need C to be strapped into a chair doing sums and things, I can think about that later on."

EXTRACT DS7:1228

"...and they don't concentrate on walking which is what people think Conductive Education is..."

A temporal difference exists between these two processes. In the first instance parents have accessed Conductive Education early in the trajectory and believe their child's physical independence to be on course. Under these conditions parents begin to think specifically of their child's academic ability.

The second process, *under conditions where Conductive Education is accessed later in the trajectory,* parents still believe their child's physical independence to be on course but do not begin consideration of their child's academic ability until later in the trajectory than the other parents. This condition is illustrated through exploration of the relationship between physical independence and potential ability.

5.3.3.7 Physical independence and potential ability - Analytical narrative

The analytical narrative states that *under conditions where a child is not enabled to perform physical tasks unaided at as early an age as possible, then the non-use of their children's limbs will perpetuate non-usage to a degree that cannot, at a later date, be overcome successfully enough to reach what would have been their child's future, physical, potential ability. Parents perceive this second scenario as resulting in a*

damage-limitation exercise - when physical independence is facilitated later in the trajectory, a child will reach a potential which has been limited by earlier non-use of limbs.

EXTRACT DS8:449

"I mean if you don't start from when they're young well they are not going to learn late on."

EXTRACT DS1A:108

"I just wish that we had started knowing about it when he was a baby."

EXTRACT DS8:746

"But it's alright saying that but if they are learnt earlier on they are benefiting later on."

5.3.3.8 Report and discussion of physical independence and potential ability

These temporal relationships indicate that parents perceive the age at which their child enrols on a programme of Conductive Education to be crucial to their future identity. Their child's academic ability and potential physical ability can be affected by late enrolment on a programme of Conductive Education to the extent that in the case of their child's potential physical independence the time lost cannot be regained to the same level as would have been achieved at early enrolment.

This issue is also extended during the laying out of the next property of the phenomenon – 'cognitive facilitation'.

5.3.4 Cognitive facilitation

A summary of what the term cognitive facilitation means in this context will serve as an aid in setting the scene for this part of the analytical story.

The term 'cognitive' in this context is not intended as a precursor to a scientific explanation of how the brain carries out complex mental functions rather, the term 'cognitive' in this context refers to those activities performed by children and seen by parents as requiring a certain amount of concentration. For able-bodied children in general and specifically in the context of the classroom these activities could reasonably be expected to include perhaps adding numbers, writing words, drawing pictures or understanding sentences (Caramazza, 1986). For children with cerebral palsy however the data for this investigation suggests that mental activity and therefore cognition is involved in every task a child performs and on every occasion that the task is performed and this is illustrated through the discussion of the analytical story.

The first stage in reporting this part of the story is to consider the properties and dimensions of cognitive facilitation, thereby setting out the specific conditions.

Table .4. Properties and dimensions of cognitive facilitation

	Properties	Dimensions	
	Mediate learning		
	Level of self-confidence	High	Low
	performance of tasks	Facilitated	Not facilitated
	Achievability	Always	Never
	Temporal	Early	Late
	Problem-solving skills		
	Transferable	Always	Never
	Temporal	Early	Late

5.3.4.1 Analytical narrative of the contextual condition of cognitive facilitation

The analytical narrative is that *under conditions where confidence building is not enabled through achievable, mediated learning programmes and problem-solving skills are not enabled early in the trajectory then parents' trust in experts is eroded and they orchestrate the identity of their child.*

EXTRACT DS1A:158

"Well Conductive Education gave you a lot of things but always made you think that nothing was impossible....it gave him that attitude...nothing is a problem to C.....we'll overcome it."

EXTRACT DS7:1280

"C's having to think constantly about what he's doing."

EXTRACT DS7:1263

"When he's sitting on the floor cross-legged you can see the concentration and the amount of thinking he's having to do...even though he might be doing something academic, he's got to think 'I've got to keep my hands here if I'm going to stay sitting up' you know 'to keep my feet apart, got to keep them flat...."

5.3.4.2 Report and discussion of the phenomenon and cognitive facilitation

Parents perceive the performance of achievable tasks through mediated learning early in the trajectory to be linked with their child's level of self-confidence and transferable problem-solving skills. In other words, if their children are enabled to perform tasks through mediated learning then the success experienced each time irrespective of the level of achievement will result in a high level of self-confidence. The high level of self-confidence in turn is transferable to problems generically so that instead of a child thinking "I can do that" the skills learned and the success experienced in the

performance of tasks are transferred to all areas of life where a problem may be encountered so that a child will think "I can't do it that way but I wonder if it will work like this."

Central to the building of self-confidence and the acquisition of problem-solving skills is that children are enabled to perform tasks and that this is done through the process of mediated learning. Deductively, this suggests that as passive receivers of education the children would not acquire problem-solving skills nor would their levels of self-confidence be high because they had not experienced the success of performing achievable tasks. This paradox has already been described succinctly by Sutton (1996) who states that "in order for the learner to make good progress ....then the learner must make good progress!" (p.7).

The process of mediated learning is also seen by parents to be an essential part of this condition. It is how and why or the intentionality of the tasks which are held by parents to be essential elements of mediated learning. In other words, the children would not attempt or achieve their tasks with the aid of an adult 'companion' untrained in the mediated process of Conductive Education. Although achievement of the task itself is not the central aim, attempting the task, in context, and experiencing the success of each step en route to completion of the task (or indeed success in the attempt) are the central issues. The transference of problem-solving is also introduced through the process of mediated learning. Here again, this is not new and has been referred to as 'transcendence' (Lebeer, 1995) but what is new is that *parents* perceive this to be happening.

Two relational links are also identified concerning cognitive facilitation:-

- cognitive facilitation and peer group dynamics
- cognitive facilitation and physical and academic independence

5.3.4.3 Report and discussion of cognitive facilitation and peer group dynamics

Parents also view the process of mediated learning to be linked with peer group dynamics in a sense that not only are individual children enabled to perform achievable tasks but the possibility of success is re-enforced two-fold. Firstly because of the experience of previous success and secondly because children have witnessed the success of their peers on similar tasks.

EXRACT DS8:322

"Well basically because it's for children with the same sort of disability....all the same sort of children trying to do, trying to aim for what they want to do...they're all doing it together and they're all looking at each other and...if you've got children that are more able he's put into that group so others can encourage him."

EXTRACT DS11:250

"I found that the special school you know had bad behaviour and it was just all overlooked 'Oh well they're handicapped' and my daughter because she can't defend herself used to come home with bite marks and all sorts of things."

5.3.4.4 Report and discussion of cognitive facilitation and physical and academic independence

The link with physical independence has already been mentioned with regard to all mental processes for children with cerebral palsy having to be enabled. This is illustrated through the data as parents relate situations in which they witness their

child's concentration when performing a task such as sitting on the floor unaided. It is the unaidedness of their sitting which caused the concentration. For example, sitting aided as in being strapped into a wheelchair requires no concentration from a child with cerebral palsy. However, sitting unaided on the floor requires serious concentration. Similarly if a child is sitting on the floor unaided with arms stretched and hands on the floor for balance and then decides to put on his/her own coat then parents describe this task as requiring a large amount of concentration for their child to be able to remain sitting whilst lifting each arm in turn into the sleeves of a coat. But the parents witness the child's great pleasure at the success of this achievement. So, 'cognitive', in this investigation represents the mental processes required to perform all tasks for the child with cerebral palsy.

The link between academic independence and cognitive facilitation suggests that it is not enough for a child with cerebral palsy to have the motivation and cognitive ability to be able to draw pictures or do number work, the child has to be able to control a pencil pen or crayon sufficiently well to be able to translate the task, through physical movements of the hand, to the paper. This returns us to the central issue of a child being enabled to perform tasks and of problem-solving skills being transferable.

In summary, parents perceive that mental processes for a child with cerebral palsy have to be enabled – they do not always occur in the natural course of childhood development nor are they necessarily performed in the same way each time as a result of practice. These issues will be illustrated further through discussion of the following analytical narrative.

5.3.5 Disability

The properties and dimensions of disability show the specific conditions under which the phenomenon exists.

Table .5. Properties and dimensions of disability

Properties	Dimensions	
Fixed		
Physical	Partially	Totally
Cognitive	Partially	Totally
Changing		
Physical	Partially	Totally
Cognitive	Partially	Totally

5.3.5.1 Analytical narrative of the contextual condition of disability

The analytical story is that *under conditions where physical and cognitive ability are deemed to be partially or totally fixed and unchanging then parents perceive the identity of their child to be off course, they become experts and take action to orchestrate the identity of their child.*

EXTRACT DS1:732

"As you get more experienced you realise that you started off with a disabled kid – you've still got a disabled kid……there are places in this world that say "Oh dear, take him away and have another'…somebody who says 'cor, yeh, let's work with him."

5.3.5.2 Report and discussion of the phenomenon of disability

Parents perceive that a programme of education that is customised to a child's current disability both physically and cognitively will result in their child's identity being off course. By current disability parents mean that if a system of education operates on an

understanding that their child cannot walk, speak, write or draw then their child will passively receive an education in a wheelchair with symbols for communication and a computer to aid in writing and drawing. In other words, the environment will be altered to suit their current disability.

There exists an important temporal shift between parents' awareness that their child's disability is not a fixed entity unresponsive to change and their erosion of trust in experts. This is specifically located along the dimensional range of the property of diagnosis and prognosis. For some parents this shift is also related to their past experiences and/or their social support system and has already been discussed in the analytical narrative of independence.

In terms of process the events occur thus. Parents receive a diagnosis of cerebral palsy from a medical expert. The diagnosis is general in terms of cerebral palsy rather than specific in terms of cerebral palsy and their individual child. Each follow-up visit and future assessment concentrates on measuring what their child is unable to do whilst parents during the vacuum between visits to experts concern themselves with their child's ability rather than disability. For parents from two families this process was perceived, by them, to be prolonged. Both sets of parents were unsupported between diagnosis and prognosis, made more difficult for one family who recalled the words used by the consultant paediatrician on disclosure - "....given the required six minutes for disclosure so your questions will have to wait until your next appointment in 3 months."

EXTRACT DS5: 918

"I was literally on my way out through the door...and I'd said goodbye and she said 'Oh, by the way, she's got cerebral palsy."

EXTRACT DS8:44

"...and his chances for survival were slim....they didn't expect him to live, obviously he did" [laughs].

EXTRACT DS11:200

"I met C's physio and she was absolutely amazed.....this was 4 or 5 months ago, that's all it was. She was absolutely amazed because she really believed the prognosis that was if he did live he would be so badly deformed and twisted you know...and he has no deformities in his body, none at all and this is a child who is the worst you can get and I'm really proud of him."

EXTRACT DS11:5

"When I was told she had cerebral palsy they just blurted it out in a couple of minutes, didn't look at me and dismissed us."

In terms of expert opinion and the erosion of trust in experts, the first encounter is of a medical rather than an educational nature but it is on the perceptions of encounters with medical experts that parents receive the advice from educational experts. The term 'expert' in this sense refers to the remote expert such as a consultant paediatrician, contact with whom would be infrequent rather than the family general practitioner or general support services personnel.

5.3.5.3 Report and discussion of trust erosion

Table .6. Properties and dimensions of trust erosion

Properties	Dimensions	
In expert advice In diagnosis In prognosis Temporal shift	Realistic General Negative Early	unrealistic specific positive late

The properties and dimensions of the erosion of trust illustrate the specificity of these conditions.

What is happening here is that parents are noticing the specific changes in their child's ability and perceive that medical experts are paying particular attention to their child's disability and offering a negative, unrealistic prognosis based upon their experience of cerebral palsy in general.

Experts cannot, of course, be specific about each individual child because of lack of continued contact. But this limitation could be acknowledged by experts through the acceptance of parental opinion as being informed. It could be deduced from this that parents' acceptance of their child's limitations and reality of their child's disability is questionable. The data suggest otherwise and is illustrated through the properties and dimensions of parents' acceptance of their child's limitations, disability and reality.

5.3.5.4 Acceptance

Table .7. Properties and dimensions of acceptance

Properties	Dimensions	
Acceptance of limitations Temporal Denial	Positive Immediate Partial	negative gradual total
Acceptance of disability/reality Miracle-seeking Temporal Private to public Denial Normalising	 Always Early Partial Partial Present	 never late total total absent

5.3.5.5 Analytical narrative of acceptance

Analytically, *parents' perceptions of their child's limitations are gradual with a temporal shift moving from negative to positive as they become more familiar with their child and as the trust in experts is beginning to erode. There is no denial of their child's disability and neither is there any element of 'normalisation'. Some parents experience an element of miracle-seeking between the temporal shift of denial of their child's disability changing from partial denial to total acceptance close to the time of diagnosis and not associated with educational options.*

5.3.5.6 Report and discussion of the phenomenon and acceptance

Only one set of parents was unable (reluctantly) to move from private to public in their acceptance of their child's disability. These parents had in fact made a total personal acceptance but were prevented through cultural stigmatisation of disability from extending their acceptance into the public domain. Parents don't expect their children

to 'snap out of' cerebral palsy but neither do they perceive a negative prognosis based on a general diagnosis to be a realistic way forward for themselves or their children.

EXTRACT DS1:13

"We also recognised that what we've got here is what we've got, we can't produce miracles....but we were very, very happy with what happened there really."

EXTRACT DS8:378

"Yeh, he will obviously need some sort of aid ....whatever he's capable of doing you know, that's what he's going to do."

On the subject of disclosure and choices available to parents Bax (1998) writes "why do parents behave this way? One answer lies in the notion that they are living in an unresolved bereavement concerning the loss of the hoped-for 'normal' child who never was, they find it difficult to be objective in evaluating information about treatment and are more prone to shop around and grasp at straws" (p. 507). Again the data for this investigation suggest otherwise.

EXTRACT DS2: 169

"He didn't come home and leap through the door on his own two feet ....you accept what the real situation is."

The actual discourse constructed by Bax and in particular terms such as 'treatment' with reference to Conductive Education and 'puzzling for parents....we professionals' are examined further in Chapter Six through the application of discourse analysis to determine why the discourse is constructed in this particular way. Its relevance here is to illustrate that 'expert' opinion considers parental choices to be ill-informed.

Discussion of the final property of the contextual conditions – potential ability –

illustrates this issue further.

5.3.6 Potential Ability

The properties and dimensions of potential ability illustrate the specific conditions under which the phenomenon exists.

Table .8. Properties and dimensions of potential ability

Properties	Dimensions	
Goal-orientated Physical Academic Achievability	 Often Often Enabled	 never never not enabled
Teaching Disorder-specific Peer group dynamics	 Always Present	 never absent

5.3.6.1 Analytical narrative of potential ability

Analytically, dangers to future identity were considered to be high and the identity off course *under conditions where physical and academic ability are never goal-orientated, and achievability of tasks is not enabled and where teaching is never disorder-specific and no peer group dynamics are present.*

5.3.6.2 Report and discussion of potential ability

Under these conditions parents take action to orchestrate the identity of their child. The action taken is reported on and discussed later in this chapter. The relational links with other properties are:-

- potential ability and independence
- potential ability and disability
- potential ability and cognitive facilitation

Potential ability has already been discussed with regard to its link with independence (p. 73-74) and is included again briefly in the laying out of the relational links between potential ability and disability; and potential ability and cognitive facilitation.

5.3.6.3 Report and discussion of potential ability and independence

From the starting point of the link between potential ability and independence already discussed, parents perceive that if their child's physical and academic independence are facilitated then their ability to perform tasks unaided is perpetuated. The properties of disability show that parents perceive the identity of their child to be not fixed but always changing. This strikes at the heart of the principles underpinning educational provision for children with cerebral palsy because parents perceive that if their child's education is not geared to their future potential then because they are not actively performing tasks but are passive recipients of their education they will not be enabled to develop the skills with which to perform the tasks in the future.

EXTRACT DS7:1161

"...in a way children are learning how to hold their bodies and um it's very difficult to explain really but physio is very passive...."

EXTRACT DS10:475

"...they don't have the philosophy that Conductive Education has in letting the children try to reach those goals themselves."

What this means in a theoretical sense is that the definition of cerebral palsy is in question. Although cerebral palsy could be described as 'progressive' in a physical sense of the word (if limbs are not used, they become more unusable), the definition of

'progressive' should not be used in the same sense as it is in, for example, Alzheimer's disease. 'Progressive' in that sense refers to a cognitive ability which becomes progressively worse, over time. But this is not how parents perceive a definition of cerebral palsy. Parents perceive that given the appropriate conditions the limitations of the progressive effects of cerebral palsy can, to a certain extent, not only be halted but also overcome. In the physical sense this means that if children are enabled and encouraged to use their limbs at an early age then their physical ability which is expected to become progressively worse will, instead, become progressively better. Because children with cerebral palsy need the use of cognitive functions to perform the taken-for-granted physical tasks of daily living then certain aspects of cognitive dysfunction could also be overcome and transferable.

In this sense a programme of education that is delivered to a child with cerebral palsy in a passive manner ignores the potential ability of a child to the extent that their future identity will be based upon their disability which is going to become progressively worse due to non-usage of limbs and mental structures.

5.4 The story so far

As an element of clarity in the complex process of reporting and discussing the conditions related to the phenomenon, the main issues which have emerged, at this point in the procedure, are briefly summarised.

Firstly, the findings suggest that if Conductive Education were to be included as an option within LEA provision, the trajectory for parents, in terms of enrolment, would be linear. However, currently, Conductive Education falls outside LEA provision,

resulting in a non-linear trajectory of enrolment.

The second major issue to emerge concerns the value attached, by LEAs, to the opinions of parents on the decision-making process. It appears that parents are considered to be ill-informed on matters of both education and disability, with parents' views being regarded as biased due to their subjective involvement. Furthermore, LEAs favour the opinions of 'experts', who have a wealth of general knowledge related to children with cerebral palsy, rather than the opinions of parents, who have specific knowledge in relation to their individual child.

A further issue arises, rather paradoxically, with regard to the 'appropriateness' of a programme of education. LEAs base their decision on a programme of education according to its appropriateness to a child's needs. However, when an LEA does not agree with the parents' choice of a programme of Conductive Education, an LEA will defend its decision through the premise of 'adequacy' - an LEA is required to provide an 'adequate', rather than a 'best', programme. Implicitly, this could suggest a recognition by LEAs that parents are striving for the 'best' provision (in their case Conductive Education) but will be offered 'adequate' (LEA) provision.

Another issue to emerge, so far, relates to the dangers, perceived by parents, to the future identity of their child. Central to this issue is the recognition, by parents, that the nature of the impact, on identity, is dependent upon the particular, fundamental underpinnings of a programme of education. Parents perceive a programme based on the current limitations of a child (LEA provision) will have a negative impact on identity whilst a programme based on a child's potential ability (Conductive Education)

will have a positive impact on future identity.

Parents also perceive the timing of enrolment on a programme of Conductive Education to be a crucial factor related to future identity for two main reasons. Firstly, because of the perception that a child's academic ability should be considered *after* issues related to physical independence have been enabled in order to complement academic tasks with physical independence. The second issue in connection with the timing of enrolment on a programme of Conductive Education concerns the definition of cerebral palsy. Here, the emphasis is on enabling physical independence, early in a child's life, in order to avoid a situation whereby limbs become unusable *because* of lack of use rather than as a result of an abnormality of the brain. This particular point has relevance to nature of cerebral palsy in terms of progressiveness (or non-progressiveness) and will be discussed in greater detail towards the end of this chapter.

The reporting and discussion process continues through consideration of the remaining conditions of the phenomenon, namely, the intervening conditions, the action strategy and the consequences.

5.5 Figure .5. The phenomenon and the intervening conditions

PHENOMENON

Orchestration of Identity

Intervening conditions

Evaluating influences

Evaluating educational options

The major categories which intervene between the context and the phenomenon are evaluating influences and evaluating educational options. How these conditions relate to the phenomenon is that parents choose to orchestrate the identity of their child in the context of perceived dangers to their child's identity and the identity course. If parents perceive the level of dangers to their child's identity to be high and the identity to be off course then they begin to evaluate the influences and their educational options and orchestrate the identity of their children.

In this sense the properties of the phenomenon namely, independence, cognitive facilitation, potential ability and disability are being recognised as factors contributing to their child's identity and future identity course at the same time as the process of evaluating these influences is occurring.

In other words the laying out of the story with regard to the properties and therefore the context of the phenomenon also represents the influencing factors.

However, there is a relationship between these factors which exists in the sense of the intervening conditions but not the contextual conditions and this is between evaluating influences and perceptions of disability.

5.5.1 Evaluating influences and perceptions of disability

Table .9. Properties and dimensions of perceptions of disability

Properties	Dimensions	
Personal		
Identity	Fixed	Changing
Temporal	Early	Late
Levels of acceptance	High	Low
Cultural	Stigmatisation	No stigmatisation
National	Informed	Ill-informed
Global	Informed	Ill-informed
Hungary		
Socio-economic climate	Matched	Unmatched
Acceptance	Early	Late
LEA	Similar	Dissimilar

5.5.1.1 Analytical narrative of evaluating influences and perceptions of disability

Analytically, *under conditions where parents' personal perceptions of disability hold identity to be changing, where a temporal shift in their levels of acceptance of their child's disability has occurred early in the trajectory (from low to high), where national and global perceptions of disability are held by parents to be ill-informed and where the only other programme of Conductive Education is socio-economically matched to Hungary and where LEAs' perceptions of disability are perceived to be dissimilar to parents' perceptions,* then parents take action to orchestrate the identity of their child.

5.5.1.2 Report and discussion of evaluation influences and perceptions of disability

To evaluate the influences parents need to make comparisons between the educational options available to them. They visit the special schools recommended by their LEAs and they visit the National Institute for Conductive Education. Sequentially, however, the perceived influences whilst broadly known by parents don't actually take a specific form until the comparisons are made.

EXTRACT DS10:623

"I must admit when we first started with Conductive Education it was all about walking ....I want C to walk, walk, walk....you began to realise that the actual walking was the icing on the cake."

EXTRACT DS5:628

"Like the professionals are not really genuine supporters of Conductive Education, they don't even mention Conductive Education to you."

EXTRACT DS7:1290

"You'd like to think that in ten, twenty years time society is going to change but society is always going to be able-bodied dominated."

EXTRACT DS1:648

"Oh I think there's plenty of ramps...you can go in with a concrete mixer...they can change toilets but can they change the philosophy of the people that have always done it this way."

5.5.2 Evaluating educational options

In effect, much of the evaluation process of educational programmes has already taken place because the influences have been identified and as these do not correspond with what parents believe should constitute an appropriate programme of education they had led to parents orchestrating the identity of their child. Similarly, with regard to the sequence of evaluating programmes of education, some of the properties of evaluating educational options have already been discussed namely, mediated learning, achievability of tasks, confidence-building, group dynamics, problem-solving skills and adaptability. The remaining properties are:-

Table .10. Properties and dimensions of evaluating educational options

Properties	Dimensions	
Whole system approach	Essential	non-essential
Harsh	Always	Never
Level of motivation	High	Low
Level of loving care	High	Low
Level of stimulation	High	Low
Challenges	Enabled	not enabled
Expectations	Present	Future
Active	Always	Never
Passive	Always	Never
Negativity	Present	Absent
Positivity	Present	Absent
Level of enjoyment	High	Low
Level of reluctance	High	Low
Duration	long-term	short-term
Goal-orientated	Always	Never
Disorder-specific	Facilitated	not facilitated
Current disability	Matched	Unmatched
Potential ability	Facilitated	not facilitated

5.5.2.1 Analytical narrative of evaluating educational options

The analytical story is that *under conditions where parents' acceptance of disability, reality and limitation is total and false hopes have shifted to realistic expectations early in the trajectory where Conductive Education is seen as a whole system of education with a high level of motivation and loving care, where achievability of tasks with high level of disorder-specific expertise and stimulation where confidence-building is enabled through mediated learning, peer group dynamics and problem-solving skills and challenges are enabled through an active, positive, adaptability with high levels of enjoyment on a long-term programme of education then there are no dangers and identity is on course.*

5.5.2.2. Report and discussion of evaluating educational options

By the time that parents begin to research systems of education they have a total acceptance of the limitations of their child's disability and any false hopes of an unrealistic outcome experienced soon after the birth of their child are gone.

Conductive Education as a whole system of long-term education is something that parents see as essential. They are aware of elements of Conductive Education being included on the time-table of some special education schools but believe that Conductive Education cannot be dipped into if the optimum benefits are to be realised. Parents also perceive that the high level of loving care existing in Conductive Education is often also present in special education systems but for a child's potential to be realised the loving care has to be accompanied by disorder-specific expertise. By this parents mean that an environment such as special education encompasses a wide variety of disabilities so that peer group re-enforcement would not be possible and without the expertise of mediated learning techniques the level of success would be low also resulting in a low level of motivation.

The goal-orientated challenges that parents believe to be an essential part of Conductive Education are perceived as being present in special education but that the goals are set for fundamentally different reasons. In Conductive Education parents see the goals as representing a particular task that a child can attempt to achieve. The actual achievement (or not) is not the central issue – the trying is the central issue and it is this that represents the success. This success remains at an individual level – it cannot be quantified. However parents perceive goal-orientated challenges in a special educational setting as representing a goal, the outcome of which will not be judged as

successful unless it is achieved and will also not belong to the individual but will be used as a measure of what a child can or cannot do. Parents do not see Conductive Education as harsh (Oliver, 1989) but understand why it is possible to think so at first glance and from the perception of traditional special education because tasks are performed unaided according to the programme for the day. Parents believe the high level of enjoyment that children experience during the day with no levels of reluctance are evidence that Conductive Education is not harsh. Parents believe that not allowing a child to reach their full potential is harsh. Parents perceive that the positivity of conductors aids in the children's high level of motivation and stimulation as well as their confidence-building and problem-solving skills mentioned earlier. That children are always active agents in their education is also an important element according to parents. Parents believe that if their children were passive receivers of a programme of education then cerebral palsy would be degenerative physically and non-progressive or degenerative cognitively thereby causing a huge difference in their future identity.

A relationship between evaluating educational options and parents' perceptions of education had also been identified. The properties of this are:-

5.5.3 Perceptions of Education

Table .11. Properties and dimensions of perceptions of education

Properties	Dimensions	
Personal		
Potential ability	Enabled	not enabled
Local (LEA)		
Potential ability	Enabled	not enabled
	Active	Passive
Mediated	Always	Never
National	Informed	ill-informed
Global	Informed	ill-informed
Hungary		
Socio-economic	Matched	Unmatched
Legislation	Parent-friendly	not parent-friendly
Partnership	Possible	not possible
Culture	Stigmatising	Non-stigmatising

5.5.3.1 Report and discussion of perceptions of education

Central to parents' personal perceptions of education is that a programme of education should reflect their child's potential ability through an active programme of mediated learning. These they see reflected in a programme of Conductive Education but not in special education programmes provided by LEAs. They see these fundamental differences as being not restricted to a local level but representing a national trend.

Parents' perceptions at a global level are centred on a knowledge of Conductive Education as practised in Hungary. Whilst recognising that the programme of Conductive Education which they have chosen is based on practise in Hungary they are also aware that adaptations were necessary to meet the different socio-economic and cultural differences of the countries.

Also central to parents' personal perceptions of education is the legislation currently in place for special education provision. They do not believe that a partnership with their LEA is possible because there is a huge divide at a fundamental level between what parents perceive to be an appropriate programme for their child and LEA provision.

5.6 Figure .6. The phenomenon and the action strategy

PHENOMENON

Orchestration of Identity

ACTION

Reclaiming Ownership

Balancing Options

Choosing Conductive Education

The action taken as a result of the orchestration of identity – parents reclaiming ownership of their decision-making process, balancing options and choosing Conductive Education – are set out.

5.6.1 Reclaiming ownership

Parents perceive the need to orchestrate the identity of their child under the conditions already reported and discussed. Parents have evaluated their educational options and now perceive the need to take action for the identity of their child to be on course. For these parents there are three forms of action necessary and these occur in parallel. They reclaim ownership of their decision-making process which they perceive at that time to be out of their control irrespective of the process of evaluating their education options. At the same time they balance the options open to them and they perceive Conductive Education as practised at the National Institute for Conductive Education to be the system of education which will lead to their child's identity being on course.

The properties and dimensions of this condition are:-

Table .12. Properties and dimensions of reclaiming ownership

Properties	Dimensions	
Control		
Experts to parents	Partial	Total
Temporal	Early	Late
Parents as Experts		
Acceptance of role	Reluctantly	Willingly
Passive recipients	Past	Present
Active negotiators	Past	Present
In education system		
Dogmatic	Always	Never
Enforced battle	Always	Never
Expected	Always	Never
Closed ranks	Present	Absent
Temporal	Early	Late
Anger level	High	Low
Degradation level	High	Low
Loss of dignity	Often	Never
Powerlessness	Present	Absent
Same old story	High	Low
Empowerment		
Identity course	On	Off
Level of danger to identity	High	Low
Differences	Fundamental	Superficial

5.6.1.1 Analytical narrative of reclaiming ownership

Analytically, *under conditions where parents orchestrate the identity of their child they reluctantly accept the role of experts so that they have partial control over the decision-making process so that their role of passive recipients shifts to that of active negotiators of educational provision but perceiving that their LEA is dogmatic in their decisions and having a feeling of closed ranks in all areas of LEAs they change from partial control to total control of their decision-making process.*

5.6.1.2 Report and discussion of the phenomenon and reclaiming ownership

These are the conditions under which the action exists for all but two parents. These two parents are the same parents who caused a temporal variation in the data earlier in

this chapter and they are also responsible for a temporal variation in reclaiming ownership of the decision-making process. For these parents the erosion of trust in experts did not happen in this data because it had, for them, already occurred due to prior knowledge of cerebral palsy and Conductive Education. Similarly, on a temporal level of the action taken, these parents did not demonstrate a shift in control (partial to total) from experts to themselves. For these parents total control of the decision-making process was perceived to be necessary because they had no trust in expert opinion prior to embarking on the decision-making process. These two parents also willingly rather than reluctantly accepted the role of active negotiators as they already perceived LEAs to be dogmatic in their decision-making process. For these parents there was also an element of 'same old story' where the issues of enforced battle to have their decision accepted came as no surprise to them neither did they experience any fresh anger, degradation or loss of dignity during the enforced battle.

For the remainder of the parents anger was expressed through the perception of powerlessness and high levels of loss of dignity and degradation (this last to be discussed more fully with regard to the action of choosing Conductive Education).

EXTRACT DS5:424

"The objective was to get a statement...and it was a case of using the legal aid process to get a statement. Once the statement is produced the legal aid stops."

EXTRACT DS6:298

"....that he was a little boy and gets tired and it drives me really angry, it makes me very angry to hear those words even today."

EXTRACT DS9:49

"'We did some fund-raising, we started fund-raising and over a period we raised.....It was degrading actually, because we were begging and things."

Existing literature suggests that parents who have children with disabilities experience anger because their child is not 'normal' and because fate has dealt them this blow (Bruce and Schultz, 1994). The data from this investigation suggests that parents do indeed experience anger but that this anger is caused by perceptions of powerlessness, degradation and loss of dignity. But it is not these feelings that lead parents to reclaim ownership of their decision-making process. Rather, it is the perception that their child's identity is off course and high levels of danger to their child's identity that create the need for empowerment – empowerment in this sense meaning empowerment of their child's identity rather than empowerment of the decision-making process although one does lead to the other.

The actual nitty-gritty of reclaiming ownership is illustrated through exploration of the parallel action – balancing options.

5.6.2 · Balancing Options

Parents have reclaimed ownership of the decision-making process after evaluating their educational options and choosing to orchestrate the identity of their child. The balancing of their options refers not just to educational options but to all of the issues involved in selecting Conductive Education as the programme of education for their child.

The properties and dimensions that specify this condition are:-

Table .13. Properties and dimensions of balancing options

Properties	Dimensions	
Potential ability	Enabled	Not enabled
Partnership with LEA	Possible	Not possible
Level of suitability	Adequate	Best
Easy fixes	Ramps	Philosophy
Mediated learning	Spasmodic	Continuous
Independence – physical	Current	Future
- academic	Physical first	Einstein second
Level of accessibility	Easy	Difficult
Expert advice	General	Specific
Role in education	Active	Passive
Bad behaviour	Tolerance	Intolerance
Legislation	Supportive	Non-supportive
Economic	Funded	Non-funded
Identity course	On	Off

5.6.2.1 Analytical narrative of balancing options

Analytically, *under conditions where parents perceive that Conductive Education offers a programme which enables potential ability, where mediation is continuous, based on future potential of physical independence, and when this is secure, there will be the opportunity to consider academic ability where their children will have an active role in their education, where bad behaviour is non-existent because of order-specific education, and where it is the best level of suitability (where expert advice is general rather than specific), where a partnership with their LEA is perceived to be impossible (because the basic philosophy is concerned with easy fixes), and where accessibility is considered to be difficult, parents choose Conductive Education.*

5.6.2.2 Report and discussion of the phenomenon and balancing options

This story sets out the avenues open to parents once they have chosen to reclaim ownership of their educational options. It also hints at the possible reasons why parents, having heard of Conductive Education, do not choose it as the programme for their

child. The properties which point to this are partnership, easy fixes, level of accessibility. These parents know that because whole-system Conductive Education is not included in LEA choices, that enrolment on Conductive Education with funding provided by their LEA is going to be difficult and because of their preference they perceive a stress-free partnership with their LEA to be impossible. They also perceive that a major fundamental difference between LEA provision and their preference is concerned with the two philosophies involved. Parents perceive that LEAs are happy to adapt an environment to suit a child's current disabilities by providing ramps etc. whereas these parents perceive that enabling a child's potential ability is a philosophy which encompasses not only current disability but future ability.

So, deductively, it is conceivable that parents who have heard of Conductive Education, and decide not to choose it, do so because of the difficulties. This is also in the data with regard to three parents who have suggested Conductive Education to friends or neighbours whose children have cerebral palsy. The friends or neighbours are aware of the difficulties involved in enrolling on a programme of Conductive Education and decide that they cannot embark on a battle. In this sense, the educational options are not evaluated and identity is not orchestrated although it could be argued that options are balanced – a decision is made on the expectation of the difficulties involved and the option is rejected.

Parents describe the possibility of enrolment on an LEA programme of education as an easy option which they would like to take advantage of if the fundamental philosophy matched their perceptions of what an appropriate programme of education for children with cerebral palsy should be based upon. Deductively it could be argued that parents

choose a more difficult route (in terms of accessibility) because they have a need to deflect their energies arising from perhaps guilt, denial, bereavement or chronic sorrow onto a worthy cause as suggested by Bax (1993). The data does not support this theory. Exploring the relational link between balancing options, emotional issues and acceptance of limitations helps to clarify this point.

5.6.2.3 Report and discussion of emotional issues

Table .14. Properties and dimensions of emotional issues

Properties	Dimensions	
Guilt (Bruce & Schultz, 1994)		
Responsibility	Current	Future
Temporal	Early	Late
sibling comparisons	Present	Absent
Intervention	Early	Late
Chronic sorrow (Lindgren, 1992)		
Trust	in tact	Eroded
Temporal	Early	Late
enforced battle	Expected	not expected
Denial and false hope (Bax, 1993)		
Temporal	Early	Late
To pour energies into	Often	Never

Analytically, a temporal process exists with regard to feelings of guilt experienced by parents. For most parents these feelings occur prior to the erosion of trust in expert opinion. Two parents who had past experience of cerebral palsy and Conductive Education did not experience any feelings of guilt before their erosion of trust in experts as this had occurred for them prior to disclosure. A shift in this temporal process occurs when parents perceive LEA programmes of special education and a whole-system approach of Conductive Education to be fundamentally different. At this time parents have an expectation of future guilt if they feel that current legislation and

funding arrangements will prevent them from securing a programme of education which will best suit their child with regard to their child's potential ability and identity course.

EXTRACT DS7:765

"..in the future if my child ever comes to me and says 'Oh why did I go to that school and not this school, why didn't you fight for me..."

There is also a relational link between the property of false hope and acceptance of their child's limitations. As parents accept the limitations of their child early in the trajectory any feelings of false hope are replaced by feelings of hope that is realistic.

Under the condition of the action parents take to orchestrate the identity of their child parents have reclaimed ownership of the decision-making process and balanced the options open to them. The third action that parents take is to choose Conductive Education.

5.6.3 Report and discussion of choosing Conductive Education

This third action which parents take to have a hand in the future identity of their child is not taken lightly. The foregoing conditions of this chapter illustrate that parents become researchers into general issues regarding programmes of special education and cerebral palsy and into their child's specific ability. With this knowledge gained they have decided to make Conductive Education, as it is practised at the National Institute of Conductive Education, their one and only choice. Given the disparity that parents perceive to exist between LEA provision and whole-system Conductive Education it is clear that they cannot make their choice a first preference rather than an only choice

because, in effect, they consider LEA provision to be based upon a fundamental philosophy which they perceive will have an adverse effect on their child's future identity.

5.7 Report and discussion of the phenomenon and the consequences

Adeo in teneris consuescere multum est

"Tis education forms the common mind, Just as the twig is bent, the tree's inclined."

(Pope, 1734)

The analytical message of the consequences of the action taken by parents – the identity of their child is on course – are set out below.

Parents perceive the dangers to their child's future identity to be of a low level and on course if:

- they reclaim ownership of the decision-making process which they have, hitherto, perceived to be out of their control;
- balance the options available to them; and
- choose Conductive Education as a programme of special education for their child

The discussion of the consequences of parents orchestrating the identity of their child draws upon the findings already discussed under the specific condition in this chapter as well as the whole picture approach represented by all of the data.

For parents from three families the consequence of their action i.e. the identity of their

child being on course, is not delayed. Parents from four families experienced a delay between their actions and the consequences of their actions because their LEA did not agree with their choice initially but their delayed statements eventually named the National Institute as the school. For parents from four families the delay was greater because their LEAs did not name the National Institute on the child's statement and would not change their decision. In these cases the decision was settled at tribunal hearings when all four statementing decisions were over-turned in favour of parents' decisions. In one of these four cases the LEA took the step of appealing against the decision made at the tribunal hearing and the attendant judge ruled in favour of the tribunal decision and took the unusual step of awarding all costs against the LEA.

For those parents who experienced a delay in funding allocations, the funding was raised by themselves through various means felt by many to be degrading. The position for all parents following enrolment at the National Institute and initial funding from their LEA is that their child is assessed by LEA personnel at frequent intervals and that funding is continued if it is shown that the child continues to make an improvement. There are two issues which require elaboration here. The first is that the assessment which takes place by LEAs when a child is enrolled on a programme of Conductive Education at the National Institute is concerned with whether a child will continue on the programme of Conductive Education or whether an LEA programme of special education will be considered to be more appropriate. This type of assessment is peculiar to children with cerebral palsy enrolled at the National Institute because although frequent assessments take place in LEA special education schools the purpose is to determine the suitability of the current regime for an individual child rather than the suitability of the whole programme, and philosophy, of education.

The second issue is that the funding of a place at the National Institute is continued only if it can be shown that a child continues to make an improvement. This issue tends to highlight the gap which parents perceive to exist between Conductive Education and LEA provision. LEAs are looking for an "improvement"whilst parents are seeking an active programme of education directed towards their child's potential ability. Many of the particular elements of what parents perceive constitutes the facilitation of potential ability cannot, through LEA assessment, be measured. Such elements are self-confidence building, transference of problem-solving skills and high levels of enjoyment in experiencing the success of attempting tasks of daily living. It is also relevant to note that in one tribunal case the evidence of a child's disability was supplied by a consultant paediatrician who had not seen the child for 18 months and declined an offer from the parents of an up-date visit. In the same case a support services report was given by personnel who also had not seen the child for a 'long time' but declined the offer by the parents of an up-date.

Clearly, intentionality and context are ignored during LEA assessment further strengthening one of the major points discussed in chapter three - that it is not appropriate to assess Conductive Education from the existing LEA paradigm of special education.

A final, but major, point on the same issue is that LEAs look for 'continued improvement' which suggests, deductively, that there is an improvement that needs to be continued. This paradox can be extended by consideration of the fact that some LEAs have introduced specialised furniture for the purposes of offering conductive-

style exercises in some schools. The gap between the two philosophies is highlighted here two-fold. Firstly, if LEAs consider it appropriate to introduce specialised furniture into some schools then it can be deduced that there is not total opposition to certain elements of Conductive Education. Secondly though, if LEAs are introducing specialised furniture for the purposes of exercise sessions then their understanding of Conductive Education is flawed. The role of the specialised furniture, as a part of the whole-system approach of Conductive Education, is to facilitate the performance of tasks rather than as props for an exercise programme. In this sense, the links that LEAs make between the furniture and physical ability are ill-informed in comparison to the knowledge-base of parents.

The consequences of the action taken by parents to orchestrate the identity of their child are, therefore, not guaranteed to be long-term.

5.8 Summary

The conditions under which the phenomenon exists have been discussed. This chapter draws together the emergent theoretical implications which address the first two aims of the investigation in identifying why parents choose Conductive Education as the programme of education for their child with cerebral palsy and these are identified as:-

- Identification of determinants which influence parents' decision; and
- How parents make sense of their decision-making process

The first aim is addressed through consideration of the contextual conditions (and therefore the properties) of the phenomenon. Parents perceive that an appropriate programme of education for their child should be an active programme of education

based on a child's ability as changing over time and in context which is directed towards their child's potential ability.

The determinants are:-

- geographical location of the family and subsequently their LEA
- Past and present belief systems
- Social support systems
- Perceptions of disability
- Perceptions of education
- Trust in expert opinion
- Acceptance of child's limitations/disability/reality
- Facilitation of independence and cognitive facilitation
- A philosophy of education that reflects a child's potential ability

The second aim of the investigation is explored through the intervening conditions and the action parents take. Parents know that they are not taking the commonly-accepted route to special education for their child. The trigger point for perceiving that they need to research educational options occurs around the time of disclosure for most parents and before disclosure for those parents who have prior knowledge of cerebral palsy and Conductive Education. At and around the time of disclosure these parents experience a vast disparity between the general diagnosis and prognosis offered by experts and the specific ability of their child. This familiarity with their child's ability raises parents' awareness of the need to become researchers in programmes of education at the appropriate time and through doing so parents experience the necessity for them to reclaim ownership of their decision-making process by balancing the options available

to them. They acknowledge that there was a time when their acceptance of their child's limitations was partially unrealistic and some parents also consider they were partially seeking a miracle cure before they became researchers and experts in their own right. Parents begin to reclaim ownership of their decision-making process because they perceive the control to lie in the hands of LEAs and that an LEA programme of education will result in their child's identity being off course.

Parents have begun to make sense of their decision-making process by their awareness of their earlier ignorance as evidenced by their pre-expert expectations being partially unrealistic. They further made sense of the decision-making by evaluating and balancing processes. For these parents a passive programme of education geared to their child's current disability will result in their child's identity being governed over the years by what they cannot do and never will be able to do instead of what they can do or what they cannot do now but could do in the future.

These are the aims of the investigation which have been addressed in this chapter. The theoretical implications emerging through the laying out of the analytical story related to the conditions under which the phenomenon exists are of a specific nature. These are:

5.9 Emergent theoretical implications

The emergent theoretical implications can be separated into two main categories. Firstly those theories that are held to be newly generated and grounded in the data and secondly already existing theories which are either:-

-supported by and grounded in the data, or

- modified by and grounded in the data.

Separated into the relevant categories for the purposes of clarity the theoretical implications are:-

5.9.1 Newly generated theoretical implications

The first implication developed through the relational links between the categories and the phenomenon is that parents perceive the identity of their child to be socially constructed through the impact of a programme of education as discussed in section 5.3.2 of this chapter. This implication feeds directly into the second theory which is developed through analysis of the data – that the differences between the fundamental philosophies underpinning Conductive Education and that of LEA provision are what parents perceive to be central to their action of orchestrating the identity of their child. In other words, the construction of their child's identity is based on the fundamental underpinnings of a programme of education to which a child is exposed. Moreover, parents perceive that an appropriate programme of education should be disorder-specific, based on mediated learning, delivered by trained personnel, based on an identity that is changing alongside a child's potential ability, through an active and positive programme of education based on the promotion of independence through the performance of daily living tasks. Parents perceive these to be central issues representing a whole system philosophy of Conductive Education as practised at The National Institute of Conductive Education.

The findings also suggest that parents who have heard of Conductive Education, but do not choose it as a programme of education, base their decision on the expectation that they will not receive support from their LEA and will need to embark upon an all-consuming battle for their choice to be realised (section 5.6.2.2).

5.9.2 Existing theories – supported

The existing theories which are supported by the data are related to parents' perceptions on a programme of Conductive Education as practised at the National Institute of Conductive Education and therefore have a bearing on *why* parents chose Conductive Education for their children. For instance, the findings through the perceptions of parents support the suggestions that children are active agents in their own development (Llewellyn and Owens, 1997) whereby if children are enabled to participate in their education programme then their development will reflect this as discussed in sections 5.5.1 – 5.5.2.2.

Analysis of parents' perceptions also supports the theory that a programme of education should be based on appropriateness to a child's needs (Wright and Poynter, 1996) rather than on notions of what constitutes adequate or best in terms of a programme – section 5.2.2. The findings also support suggestions by Hall and Hill (1996) that their opinions are not biased in terms of being hopelessly exaggerated and unreliable due to their proximity to their situation (5.5.2). There is also evidence in support of the suggestion by Sutton (1996) that the acquisition of transferable skills such as problem-solving as well as the development of self-confidence would not be possible unless children were presented with opportunities in which to experience success (5.3.4.2).

Parents' perceptions also suggest the importance of mediated learning as central to the practice of Conductive Education as suggested by Lebeer (1995) (5.3.4.2) as well as the notion that positive attitudes to education address the issue of the appropriateness of children with disabilities being measured through an understanding of their limitations (Drench, 1994) (2.2., 5.5.2.2.).

These theories are related to the *disparity* which exists between parents' perceptions of an appropriate programme of education and the perceptions of LEAs. Central to this disparity is the notion that a programme of education should be chosen because of its appropriateness to the needs of a child (rather than whether it is adequate or best) and that an appropriate programme of education be underpinned by children being seen as active agents in their own development.

5.9.3 Existing theories – modified

The existing theories which are not supported by the data are, in the main, related to the notion that parents are ill-informed suggesting, implicitly, that parents have chosen a programme of Conductive Education for reasons that do not involve a process of evaluation, either knowingly or unwittingly.

Although these existing theories are related to influencing factors for parents in the decision-making process, they portray parents as passive and not active agents in a process which is not static but changes over time and within specific contexts.

Suggestions by Oliver (1989) that Conductive Education is harsh is not supported by the data. Parents understand that it is possible to have this view of traditional special education but perceive the high levels of enjoyment and a total lack of reluctance indicate that Conductive Education is not harsh and this is discussed more fully in section 5.5.2.2.

Also, suggestions that parents choose Conductive Education because they are seeking a miracle cure (Bax, 1993) or 'something' to pour their energies into (Bax, 1998) are not supported in the data (5.2.2, 5.3.5.4 and 5.6.2.3.) and this point in particularly evident through the temporal shift of parents' perceptions of a programme of Conductive Education.

With regard to the notion that parents experience anger, guilt or chronic sorrow because of their child's disability as suggested by Bruce & Schultz (1994) the findings suggest that parents do indeed experience anger but that this anger is related to their experiences of powerlessness when their opinions are not valued and is not related to feelings of guilt (5.6.1.2.).

Finally, with regard to the possibility of the non-existence of links between a child's physical ability and independence (Read, 1995) the findings of this investigation into parents' perceptions suggest that physical ability is one of the elements which is linked to independence (5.3.3.1, 5.10). However, the context in which a relationship between physical ability and independence was first sought by Read (1995) was one in which the media portrayed Conductive Education as a system of rehabilitation solely concerned with enabling children with cerebral palsy to walk. Therefore, in this respect, the findings, whilst not supporting the non-existence of links between physical ability and independence, nevertheless agree with the notion that Conductive Education is not solely concerned with enabling children to walk.

The findings through the application of the grounded theory method of enquiry have highlighted theories that are newly generated, existing theories that are supported as well as existing theories that are modified.

These issues are reported and discussed as the analysis unfolds throughout the chapter and are highlighted above for the purpose of clarity. The next section (5.10) focuses upon the implications of the newly generated theories before further exploration in Chapter 6.

5.10 Discussion summary

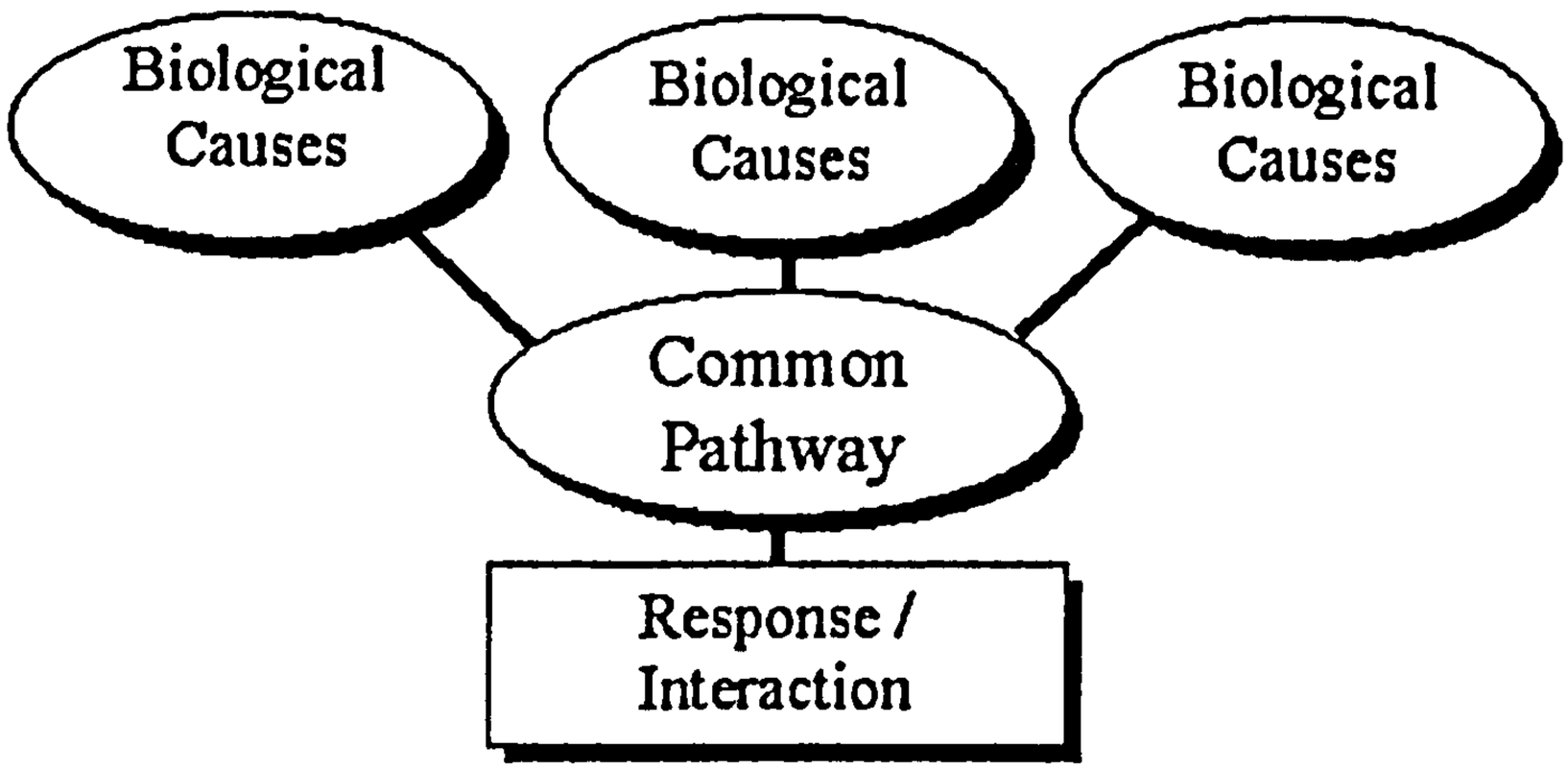
The first major implication is that parents perceive the identity of their child to be socially constructed in the sense that the type of programme of education that their child is exposed to will impact upon their child's future identity. This implication arises from parents' perceptions of Conductive Education, as practised at the Institute, representing an active programme of education based on the potential ability of their child. Parents view the alternative (LEA provision) as a passive programme of education, based on a child's current disability. In other words, a programme of education based on what a child cannot do, with the expectation of what a child will never be able to do, will result in a child's identity remaining static - the identity is socially constructed to represent *inability*. However, if a programme of education is based on what a child might be able to do in the future, given the appropriate opportunities in the present, then the social construction of identity may result in an achievement of potential *ability* as well as the experience of success in trying.

The second implication is that a programme of education will impact upon the actual self-hood of their children. The nature of this impact is determined by the fundamental philosophy underpinning a programme of education as evidenced by the disparity between what parents perceive an appropriate programme of education should offer (Conductive Education) and local education authorities perception of an appropriate programme of education as evidenced by their provision.

A third major general implication is that the definition of cerebral palsy with regard to its progressive and non-progressive nature can be brought into question depending on the type of programme of education a child experiences. Parents perceive that a programme of education based on a child's potential ability rather than current disability can change the potential definition of cerebral palsy.

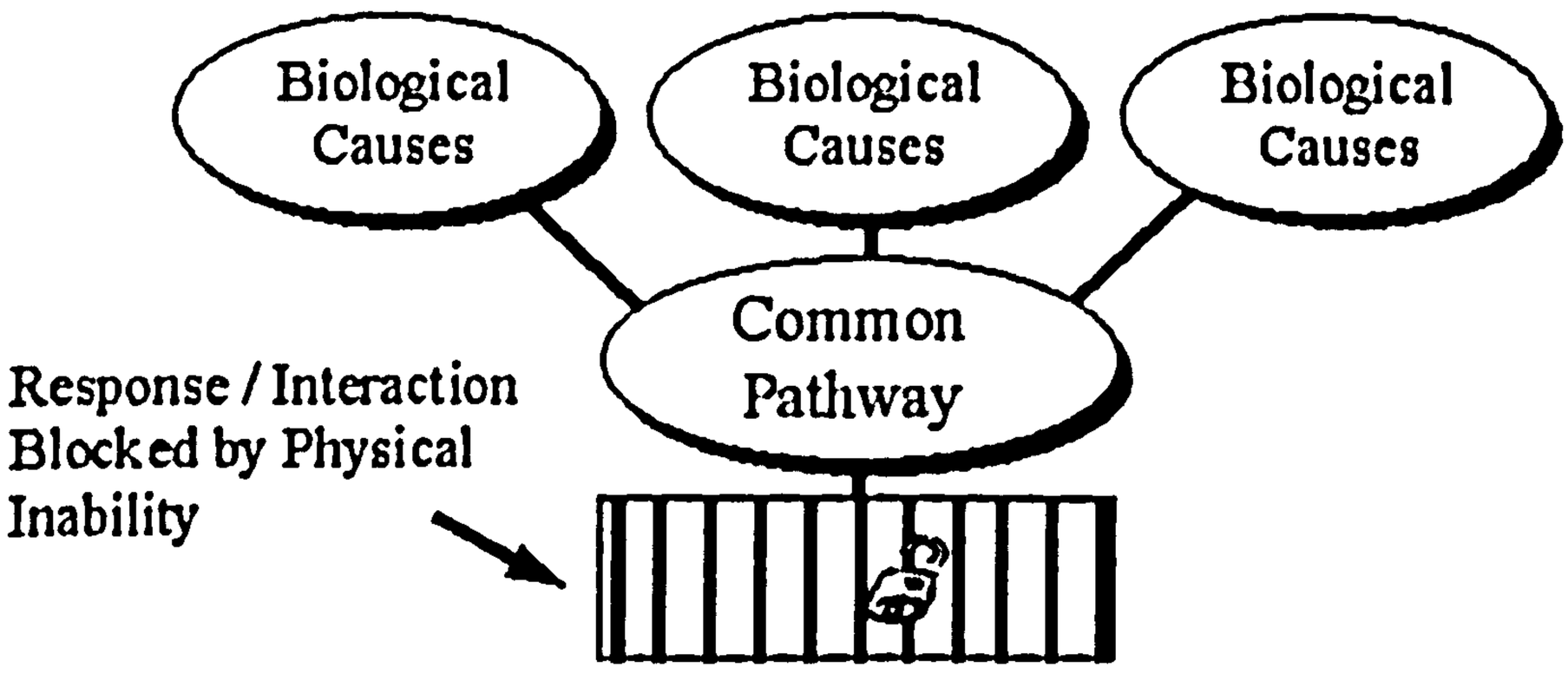
This implication is related to the possible irreparable nature of a cognitive deficit. It is possible to draw parallels here between autism and cerebral palsy. As is the case in children with autism, research suggests that an inability to interact spontaneously or appropriately with the environment is not, in all cases, due to a cognitive deficit (Frith, 1992). It would appear that the deficit (for want of a better term) is manifest because of a child's physical inability to respond immediately or spontaneously to a cognitive request. A clear illustration of this concept as well can be drawn from Frith's (1992) developmental disorders model - Appendix VI. An adaptation of this model to represent what parents perceive to be happening developmentally and cognitively could, deductively, look like those set out below. These are illustrated in several stages for the purposes of clarity.

Figure .7. Developmental processes *without* the presence of cerebral palsy



As an adaptation of the Frith (1992) model of developmental processes with regard to autism (Appendix VI), Figure .7. depicts a simplistic model of the pathways which could be representative of developmental processes without the presence of cerebral palsy. In this model, the several (but not specifically identifiable) biological causes lead to a common pathway for cognitive functions. A clear route through the pathway results in an appropriate response or interaction.

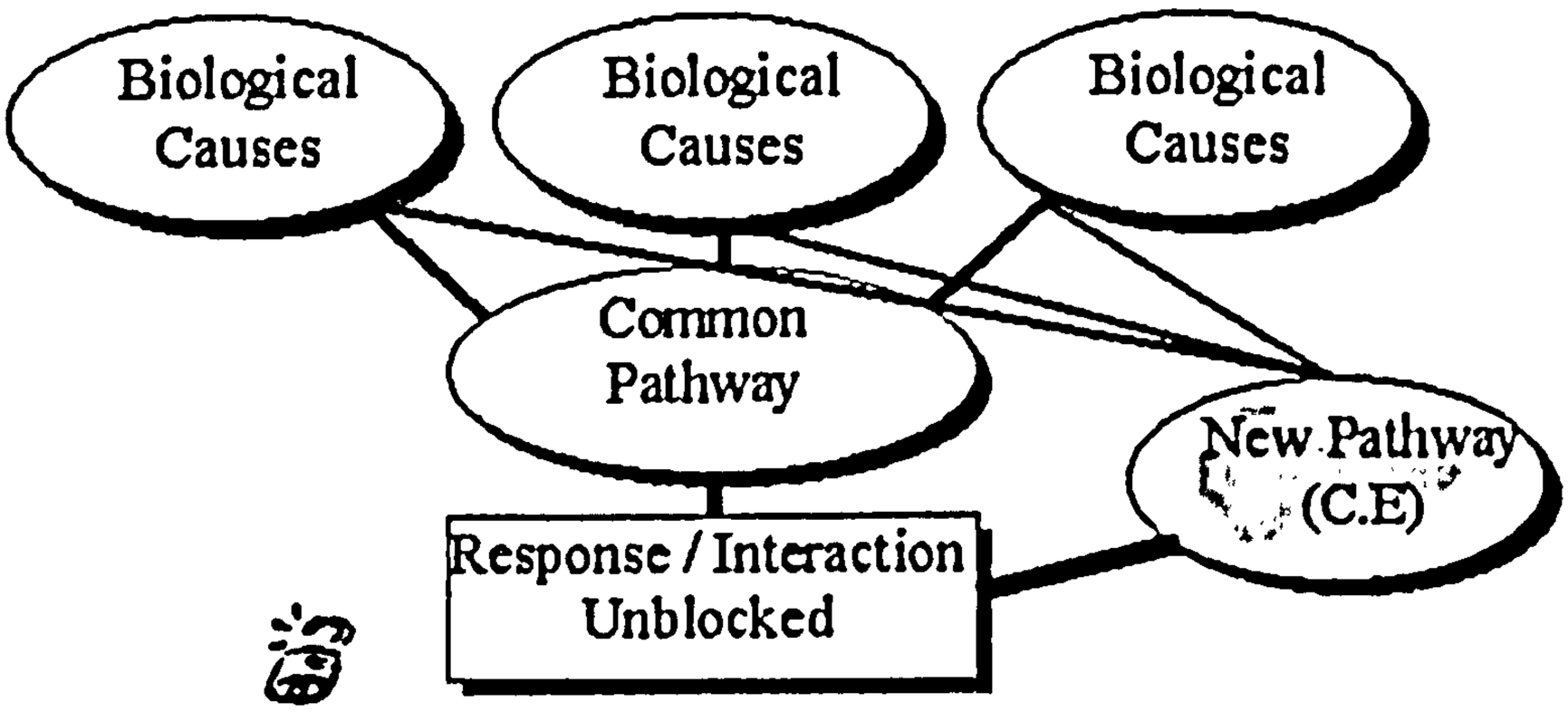
Figure .8. Developmental processes *with* the presence of cerebral palsy but *without* Conductive Education – parental perceptions



This model represents cognitive function when cerebral palsy is present but in the absence of a programme of Conductive Education. Parents identification of 'cognitive functioning' is represented by their child's level of concentration. In this case, the

common pathway has no clear route to the expression of a response or interaction because the cognitive functions are not enabled. In this sense, a passive programme of education would not enable a child, for example, to put on a coat or drink from a cup unaided or to ask a question. The coat would be put on the child, the cup would be held and symbols used instead of speech.

Figure .9. Developmental processes *with* the presence of cerebral palsy and *with* a programme of Conductive Education



The final model of developmental processes represents the development of new pathways through the enabling process of a programme of Conductive Education. A conductor would facilitate the tasks enabling a child to attempt to put on a coat, to attempt to drink from a cup and to attempt to hold a pencil. It is only through the opportunities provided by the facilitation that a child will 'find a way' as evidenced by the data:

Extract 1A:l,170

"..nothing is a problem to .....he'll overcome it, he'll get round it um, you know because he's disabled there's a number of things people say 'Oh, he can't do that'....but it doesn't matter."

The inference from the data is that for a cognitive function to reach fruition the child

needs to concentrate and, through the enabling aspect of Conductive Education, no task is so great that it cannot be attempted.

In this sense, cerebral palsy is not a physical impairment which becomes progressively worse over time. Rather, cerebral palsy often manifests, in a physical way, the inability to perform cognitive tasks spontaneously resulting in a lack of response to, or interaction with, the environment. Without a facilitator between the environment and the cognitive request, it is possible that the physical symptoms could become progressive because of lack of use.

However, without further exploration through a research question directed specifically to the processes of cognitive development, the foregoing models of development remain tentative. It could be argued that the models are representative of conceptual leaps beginning at parents' perceptions of issues of 'concentration', and culminating in a model of cognitive development which is representative of cerebral palsy with the presence of a programme of Conductive Education.

However, whilst the parallels between Figure 9 and the model proposed by Frith (1992) with regard to autism might suggest a conceptual leap, there is one major issue that appears to be common to both suggestions and this is related to the enabling factor. In this sense, the main issue is not concerned with whether the cognitive deficit causes an inability to interact with the environment or whether the deficit appears because of the inability, the major issue is that the development of pathways as a result of an enabling process with the environment. Furthermore, it may also be possible that rather than new pathways being developed (or indeed constructed) to compensate for a deficit, that

functional co-ordination is being recovered (Lebeer, 1998) through the process of enablement provided by conductors. This last concept is based on an understanding of the brain, as a human organ, being open to both change and exchange with the environment.

Clearly, if the above suggestions are tentative in nature, the question arises - why include them? The importance of their inclusion is two-fold. Firstly, whilst the information offered, by parents, was not based on either findings from brain scans or an in-depth knowledge of the plasticity of the brain, the data are clearly linked to the processes of 'concentration' and, as such have a bearing on cognitive functioning. Furthermore, parents perceive that children with cerebral palsy should enrol on a programme of Conductive Education as early as possible in order to gain the maximum benefit with regard to their future potential. This particular concept is supported by Rosenzweig and Bennet (1996) who are, indeed, conversant with 'compensatory plasticity'. Secondly, the discussion of these issues is intended as a possible precursor to further enquiry. Enquiry that is based on the child as an individual with impairment that is also unique, both of which are open to change. From this point of view, any prognosis would be offered with caution as suggested by Lebeer (1998).

A final generic implication is related to parents who have children with cerebral palsy who do not choose a programme of Conductive Education for their children. Parents in this investigation perceive that for many an awareness of an enforced all-consuming battle to receive funding from their local education authority to enrol on a programme of conductive education is a major influencing factor in this respect. Evidence for this theoretical implication is based on participants' conversations with parents who have

not chosen a programme of Conductive Education for their child as well as their expectations of an enforced battle based on their previous knowledge from parents who had entered the process at an earlier date and chose Conductive Education.

These implications from the newly generated theories as well as the expectations from the existing theories that are supported or modified through the findings in this chapter suggest that there are two higher order (generic) theoretical implications which link the first order theories and these can be explored further. These two issues, which are pivotal to parents choosing to orchestrate the identity of their children, are that parents' perceptions of the fundamental philosophical underpinnings of an appropriate programme of education are different from the perceptions of their local education authority. The second issue is that parents' opinions are ill-informed or under-valued. Both of these issues are identified because of the parents' perceived need to orchestrate the identity of their child. If parents held the same perceptions on the fundamental philosophical basis of a programme of education and/or their opinions, as partners in the decision-making process, were held to be informed and were valued it is possible that the phenomenon would not exist and this is where engagement with meaning becomes a central issue.

To summarise, the application of the grounded theory method of enquiry has uncovered specific and generic theoretical implications from the data. Two major implications are identified as linking these first order theories to form higher order theoretical implications.

Whilst grounded theory has been ideally suited to exploring parents' perceptions of Conductive Education as practised at the National Institute in Birmingham and, through doing so has offered an insight into parents' decision-making process, there is a further element of enquiry which cannot be explored through the application of this methodology. Grounded theory is not able to consider the underlying assumptions or constructions embedded in the text. In order to take the investigation one step further a second methodology is identified for the purpose of exploring the emerging theoretical implications and justification for this decision is set out in detail in chapter six.

To this end, the central theoretical implications emerging through the application of the grounded theory method are investigated further through the use of the second methodology, discourse analysis (Potter and Wetherell, 1994). The discursive nature of data from two sources – a local education authority and parents – concerning one event – a tribunal hearing – are examined to determine how the two versions of one event are constructed and why they are constructed in a particular way – Chapter 6.

Chapter Six: Emerging discourses explored through the application of Discourse Analysis

This chapter sets out the nature of enquiry through the application of discourse analysis. Dissemination of the methodology reveals the specific aims and tactics for this part of the investigation.

6.1 Introduction

One aspect of the decision-making process that has not been uncovered through the application of grounded theory is the discursive nature of certain influences on the decision-making process. Harré (1991) suggests that the resources drawn upon to reach a decision are basically discursive and embedded in the cultural community.

Inductively and deductively, in this sense, most of these parents had entered a new culture - childhood disability and childhood education. They did not have a long-standing, extensive framework from which their decisions would be influenced by their cultural discourse. Most parents entered this culture some time between the birth of their child and disclosure. Their non-acceptance of cultural expertise occurred around the time of diagnosis when they perceived the cultural discourse to be negative. Erosion of trust in cultural expertise was largely due to the general and negative nature of the cultural discourse. At this time parents perceived that they didn't agree with the advice they were receiving but did not feel knowledgeable enough (as new entrants to the culture) to determine what they perceived to be an informed account. Parents largely attributed this phenomenon to their ignorance of their new culture and so sought to become experts themselves.

For the parents who had entered the culture at an earlier time (who had prior knowledge of cerebral palsy and conductive education) the need to become experts was absent, they were established members of the cultural base. For these parents the cultural discourse in which they were engaged was expected and served as confirmation, to them, of their current perceptions.

Parents as informed decision-makers appears to be pivotal to the entire phenomenon identified through the grounded theory method of enquiry. For those parents who recently joined the culture of childhood disability and who subsequently sought to become experts in this culture the emerging central issue also appears to be that their opinion is not valued as much as that of the professional experts.

To recap, historically, prior to the Warnock Report (1978) the needs of children with disabilities lay primarily in the hands of the medical profession. Since the Warnock Report the responsibility for educating children with disabilities shifted to include the education sector in the form of Local Education Authorities the premise of which was that all children with special educational needs were entitled to an education. Since the introduction of the Code of Practice (1994), parents have now become partners in this process.

If this is the case then parents should share equal responsibility and therefore be equal partners in the decision-making process but the anger that parents express at having their opinions dismissed (revealed through the application of grounded theory - chapters four and five) warrants further investigation into the role that the other partners (medical

profession and LEA) believe parents play in the culture of childhood disability and education generally and the decision-making process in particular.

Investigation through the application of the grounded theory method of enquiry has revealed two major implications with regard to the social construction of identity - themes that are central to this study. The first is that a programme of education will impact upon the actual self-hood of a child and the nature of the impact is determined by the fundamental philosophy underpinning a programme of education. Secondly, having perceived this, parents wish to have a hand in this construction by choosing what they consider to be the most appropriate programme of education to meet the needs of their child. However, they perceive that their opinions are under-valued in comparison to 'expert' opinion in this field.

The application of the grounded theory method of enquiry has revealed the specific influences on the decision-making process for parents who have chosen Conductive Education, as it is practised at the National Institute, for their children with cerebral palsy. Also revealed is how these parents make sense of their decisions.

Embarking on a second method of enquiry with the findings and knowledge of the first offers an unusual opportunity for the adoption of a quasi-reflexive process before moving on. This process does not attempt to look again at *all* of the first methodology from the standpoint of the knowledge gained in carrying it out. Instead, the final stage of the grounded theory method will be explored and the findings examined (in light of the findings found!) in order that the second methodology may begin not just where the first ended but will attempt to move the emerging theoretical development (obtained

through grounded theory) one step further by exploring major findings from a different angle. To this end discourse analysis is applied to offer the opportunity of engagement with meaning (Burman & Parker, 1993; Potter & Wetherell, 1987 and Stenner, 1993). The theoretical basis is set out in consideration of the conceptual framework of this approach.

Three discourses are identified for the purposes of analysis and discussion and these are objectivity vs subjective experience, negativity vs positivity and current disability vs potential ability. The theoretical perspectives are explored and are related to the history of science and the allocation of 'truth' and the appropriateness of the medical perspective on matters of an educational nature.

To summarise so far, parents have entered a culture with which they are unfamiliar. Initially, they rely on the advice gained through experience and expertise to guide them through this new territory. At an early stage parents perceive that, even though they consider themselves to be ill-informed, the guidance they are receiving does not appear to be appropriately concerned with their individual child. In order to address this imbalance parents decide to become experts themselves in the, to-date, unfamiliar culture in general and how it relates to their child in particular. In this way parents perceive that their decision-making process, in partnership with medical profession and LEA will be informed. But the grounded theory data show that LEAs and parents seldom agree on the most appropriate programme of education for a child thus leading parents to orchestrate the identity of their child by reclaiming ownership of the decision-making process (Chapters four and five).

6.2 Discourse Analysis: A conceptual framework

There are wide variations in the application of discourse analysis with this methodology sometimes viewed as being divided into two traditions, historically - Foucauldian approaches to discourse (Foucualt, 1977; Parker, 1995) and interpretative repertoires (Potter & Wetherell, 1987). The essence of the foucauldian tradition of discourse analysis is that the analysis of discourse enables the identification of a subjectivity, power and ideology that make a discourse possible (Parker, 1994) and the cultural context in which language is able to make sense. Elements of the foucauldian tradition have often been incorporated into various fields of psychological theory (Rose, 1989; Walkerdine, 1993; Burman, Aitken, Alldred, Allwood, Billington, Goldsberg, Gordolopez, Heenan, Marks and Warner, 1996) with the main discussion being centred around the construction of particular discourses. In this sense, our experience of the world and how we behave in it is shaped by the structure and shared patterns of the discourses involved (Burman & Parker, 1993).

Although not completely isolated from the foucauldian tradition, interpretative repertoire is not concerned with ideology and/or power in the sense of a broad understanding of a discourse. Instead, interpretative repertoires tend to give consideration to the assumptions on which the identified repertoires rest (Potter and Wetherell, 1987).

Either of these traditions (assuming a division exists) would offer opportunities to engage with meaning - through the identification of the construction and function of the discourse or the identification of the assumptions on which the repertoires rest. However, for the purposes of exploring the documentation concerned, for this

investigation, it is considered inappropriate to assign the analytic technique to one tradition or the other. Indeed, the act of assigning could, possibly, also serve to *confine* the process of exploration. To this end, the documentation is explored to determine the basic assumptions upon which the repertoires rest as well as the construction and function of the discourses involved. Engagement with meaning will take place in the context of childhood disability and childhood education in order to highlight the issues involved.

There is, however, a factor which is common to all traditions – discourse analysis is concerned with the analysis of language whether it is the spoken word, written word or non-verbal communication (Burman and Parker, 1993) and this is an important point with regard to the first stage of the analysis which is set out in full later in this chapter.

6.3 From grounded theory to discourse analysis

The theoretical framework emerging through the application of grounded theory (Table .1.) sets out the main findings through the application of the grounded theory method of enquiry. Arrival at the theoretical framework through grounded theory has necessitated emersion in the data over a long period of time and therefore the issues which would normally emerge through the coding procedures of discourse analysis i.e. the discourses in operation can be identified through the application of grounded theory.

As already discussed in chapter three, through the application of the grounded theory method of enquiry and the subsequent identification of the central issues surrounding parents' perceptions on a programme of Conductive Education, it is also possible to

highlight the discourses involved in parents' decision-making process. The importance, and indeed relevance, of applying a further element of enquiry is set out below.

To recap, links between the phenomenon – the orchestration of identity – and the conditions under which this phenomenon exists have offered an insight into not only *what* is happening in the data but *why* it is occurring (for example contextual and intervening conditions and action taken and consequences of action – chapter five). However,k eventhough the emerging implications are based upon data concerning the perceptions of parents there is also a further version of events embedded in the text which is based on parents' perceptions of LEAs reaction to their choices as well as LEAs as 'other' providers. Hence, although the text analysed through the application of the grounded theory method of enquiry represents the perceptions of parents, it is also representative of the perceptions of LEAs – through the action taken. In other words, the action of LEAs has, more often than not, been to disagree with the decisions made by parents. Therefore, there are contextual meaning of *what* is happening in the data and *why* which shift the enquiry beyond the central issues and their conditions to the assumptions that are embedded in the text through the construction of the two versions presented – parents and LEAs. These assumptionscannot be investigated further through the application of grounded theory because they are associated with the construction of the discourses involved. These discourses are identified through familiarity with the data as well as consideration of the major implications emerging through the application of the grounded theory method of enquiry. These two major implications suggest that parents choose a programme of Conductive Education as practised at the National Institute in Birmingham because of the difference they perceive to exist between their chosen programme and traditional programmes of special education on offer through their LEAs. In a sense, this implication represents

what is happening in the data. With regard to *why* this is happening, it appears that parents perceive a traditional programme of education to be based on a child's current disability by focussing negatively on the disability through a measurement of limitations. The two discourses in operation in the data are identified as current disability versus potential ability and negativity versus positivity. A further, third discourse is identified and is related to the implication that parents' opinions are ill-informed and therefore LEAs seldom agree with the choice that parents' make. It is possible that the report that is considered, by some, to be the definitive statement on Conductive Education (Bairstow et al, 1993), and which is discussed fully in chapter two, may contribute to the reason *why* LEAs more often than not, do not agree with the choice made by parents. In other words, there is no scientific evidence to indicate that Conductive Education will offer superior benefits over traditional programmes of special education. If LEAs supported the choice made by parents then this would suggest evidence in support of parents' perceptions being considered, by LEAs to be informed and subsequently valued. However, this is not the case and, together with issues related to parents choosing a programme of Conductive Education because they are seeking a miracle cure or are in need of something to pour their energies into (which is discussed fully in chapter five) the third discourse is identified as objectivity versus subjective experience.

It is important to note at this point in the investigation that there are many discourses in operation throughout the data but certain, albeit pragmatic, decisions are necessary with regard to the identification of relevant discourses and these are primarily based taking the emerging developments one step further and are, therefore, directly related to those discourses surrounding the two major implications referred to above.

Whilst discourse analysis is applied to LEA documentation (set out fully in section 6.6. of this chapter) the connection between the documentation itself and the implications which emerged through grounded theory analysis represets further investigation of issues surrounding parents' perceptions of a programme of Conductive Education.

6.4 Research Aims

The specific events leading up to the documentation to be analysed in this chapter, arose as a result of one family deciding that an appropriate programme of education for their child is that provided by the National Institute for Conductive Education in Birmingham (although this is not to suggest that only one family experienced this process, rather that the issues are explored through the experiences of one family). Their LEA did not agree with this choice and recommended a special education school as being most appropriate to meet the needs of their child. The family visited the recommended special education school but did not agree that their child's needs would be appropriately met at the school. The LEA did not visit the National Institute. The parents submitted an appeal against the LEA decision, resulting in a tribunal hearing.

The aims of this part of the investigation are to

- determine how the event is reported by two opposing parties - the function
- determine why the event is constructed in a particular way - the construction

through analysis of the three discourses involved:-

- objectivity vs subjective experience
- negativity vs positivity
- current disability vs potential ability

Discourse analysis will be applied to documentation of one event - the statementing process and related tribunal hearing on the allocation of one place on a programme of education - by two parties - parents and LEA.

Enquiry through grounded theory has established *one* interpretation of what is going. Similarly, the application of discourse analysis will also offer *one* interpretation of events.

6.5 The paradox of writer-construction addressed

In order to explore the function and construction of the documentation which is central to enquiry through discourse analysis the paradox of writer-construction occurs. This refers to the ways in which the words used by the researcher to present an analysis of the documentation also serve to impose their own construction by the choice of words considered, by the researcher to be best suited for the purposes of laying bear the argument. This is the paradox - to present the argument the analyst could confound the analysis through the use of the words chosen.

The problem of subjective reading (Parker and Burman, 1993) of the text (also central to discourse analysis) has already been clarified by acknowledging that the analysis offers *one* interpretation, not a 'truth'.

Another issue is that parents as participants have not been provided with the opportunity to comment on their own accounts which could have awarded participants equal status between researchers and respondents (Sherrard 1991). This issue could suggest that the

researcher's account could be allocated more 'truth', by its presentation, than the text of the participants.

In order to address these important issues a further, rather uncommon, reflexive, tactic is applied to this part of the investigation. Whereas reflexivity often occurs following on from (and as a consequence of) the preceding sections of analysis and discussion, instead, reflexivity will occur *in parallel* to the analysis in a similar style to Mulkay (1985) and Ashmore (1985).

Also, being ever conscious of the welcome voices of mentors commenting on the particular words chosen to present the analysis, a parallel reflexivity (although perhaps quasi-reflexive) should also utilise the 'voices' to the fullest extent in the sense of a sort of justification for the chosen words.

The discovery of the suitability of the element of a parallel reflexivity also, to some extent, caused a paradox of its own. Its use, in a sense, produces a relinquishment of the enquiry being scientific by attempting to deconstruct any scientising-elements from the presentation of the analysis. So what sort of enquiry is left if the beginning was scientific and the scientising is removed, questions Mulkay (1985) - will this add to or detract from the beast? One way of addressing this issue would be to provide a reflexive chapter on the parallel reflexivity but this would rather defeat the object of the exercise. Instead, the reflexivity occurs within the boundary of the analysis on which it is reflexive. To this end, words appearing in italics in the analysis and discussion sections of this chapter represent the parallel reflexivity occurring.

6.6 Method

6.6.1 Materials

The exact nature of the documentation includes:

- Medical report
- Parents' views
- Educational Psychologist's Report
- Statement - LEA

(Appeal under section 326 of the Ed. Act 1996 against the contents of a statement of special educational needs)

Further evidence

- Bax (1993) Conduction Education Assessed. Developmental Medicine and Child Neurology, 35, 659-660 - Appendix II.
- Bax (1998) 'A treatment that works' (Editorial). Developmental Medicine and Child Neurology; 40, 507 - Appendix III.
- Tribunal guidelines - Appendix IV.

The documentation itself is related to one family, one LEA and the evidence gathered by the LEA to support their decision. The use of specific text from the documents could therefore have caused problems in maintaining the level of anonymity required for such an investigation. However, and rather unusually, the central issue of whether parents' decisions are considered by the experts to be informed and which represents the discourse of objectivity vs subjective experience is, in the most part, analysed through pre-printed documentation minus the text (which is clarified in the procedure section of this chapter which appears next). The further discourses of negativity vs. positivity

and current disability vs. potential ability are also analysed, in part, without specific reference to the text.

6.6.2 Procedure

Firstly, the construction of events (the statementing process) by the two parties will be explored for similarities or differences. So, whilst the documentation will in effect be deconstructed the purpose will not be to examine the structure of the sentences or the adequacy of the propositions in the style of Derrida (1974) or Wittgenstein (1958). Nor will the documentation be explored for evidence to support one particular version of events over the other. Rather, the implied meaning of the narrative will be explored. In other words, the discourse analysis is not applied to locate where the 'true' version of events lay but rather to explore the function of the reports and why they are constructed in a particular way (Gergen, 1973; Shotter, 1989 and Harre, 1989).

The exact nature of the documentation is, for the most part, in the form of questionnaires and reports which in itself may suggest that a sensitive or controversial area is being discussed (Drew, 1984). The construction of fact, in this sense, could be intended to represent a credible version of events which is least likely to be undermined (Potter, 1984). A primary examination technique will therefore involve exploration of each version of events to establish methods used by the two parties. Each version of events is analysed against each other thereby removing the enquiry from being based on some sort of pre-existing reality.

Secondly, the foucauldian style of why the versions of events are constructed in a particular way will offer a broader view of what is happening in the data. In other

words, the first part of the analysis will attempt to uncover the particular techniques of each party in constructing their version of events. The second part of the analysis will concentrate on what each party hopes to achieve by their particular construction as well as the assumptions upon which the versions rest.

As the analysis is concerned with a statementing process and subsequently a tribunal hearing, it could be suggested that the construction of events are strongest - the participants cannot reach agreement on an appropriate programme for a child with cerebral palsy and so it could be reasonably expected that the discourse will represent opposing perceptions of evidence in support of each version. In effect, the evidence will represent a form of contesting a cultural discourse (Carborough, 1996) – in this case childhood disability and childhood education.

6.6.2.1 Stages of Analysis

The stages of analysis which lead to the final analytical procedure of the discourses identified are:

Stage 1

Documentation: questionnaires

- Medical report
- Parents' views and
- Psychologist's report

Analysis of - space provided for responses to questionnaires from 3 sources as the basis of evidence gathered by LEA for preparation of Statement.

Stage 2

Documentation: questionnaires

- Medical report
- Parents' views
- Psychologist's report

Supporting evidence: Tribunal guidelines (Appendix IV)

Analysis of – pre-printed headings, questions and explanatory notes contained in questionnaires from 3 sources as the basis of evidence gathered by LEA for preparation of Statement

Stage 3

Documentation: Statement – LEA

Analysis of – amount of evidence, from 3 sources, contained in Statement and upon which statement is made.

Further evidence:

- Bax, M. (1993) – Appendix II
- Bax , M.(1998) – Appendix III

Stage 4

Documentation:

- Statement LEA
- Medical Report
- Parents' views
- Psychologist's report

Analysis of – text contained in documentation which represents the discourses involved and the theoretical perspectives involved.

6.6.2.2. The discourses identified

The data are re-ordered to represent the three discourses:

- objectivity vs subjective experience
- negativity vs positivity
- current disability vs potential ability

and these are set out in the analysis.

6.7 Analysis and Discussion

Examination of the documentation through discourse analysis has revealed the main issue to be concerned with parents as informed partners in the decision-making process. The three discourses are centred around objectivity versus subjective experience; negativity versus positivity and current disability versus potential ability.

A part of the technique for the reporting of the findings through discourse analysis could be considered rather unusual because it is not concerned exactly with text of one party or the other. Neither does it require extensive analytical procedures for an interpretation to emerge (although the element of obviousness is due in part to familiarity with the issues involved and gained through the application of the first methodology).

The use of the term 'documentation' as opposed to text is quite deliberate here. It has already been, albeit briefly, established that the major issue for analysis - are parents truly equal partners in the decision-making process - will be determined from a rather unusual source. The source itself is not unusual - questionnaires completed by three

parties - parents, consultant paediatrician and educational psychologist - required by LEA to complete a statement. The uncommon factor stems from the fact that the initial analysis is not based on text but rather the allocation of space on questionnaires for text to be provided by three parties. This forms a part of the analysis.

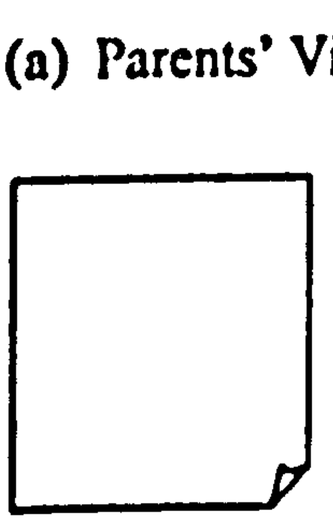
Burman et al (1996) points out that this suggests the meaning of the discourse was pre-existing but, as parents had not been a part of this context before, it could be argued that what was 'collected' did not already exist but was constructed during the interview and was context-related.

As already stated, the aims of this part of the investigation are to determine the function of the documentation, its construction and the underlying assumptions these are explored through analysis of the discourses involved.

6.7.1 The discourse of objectivity versus subjective experience

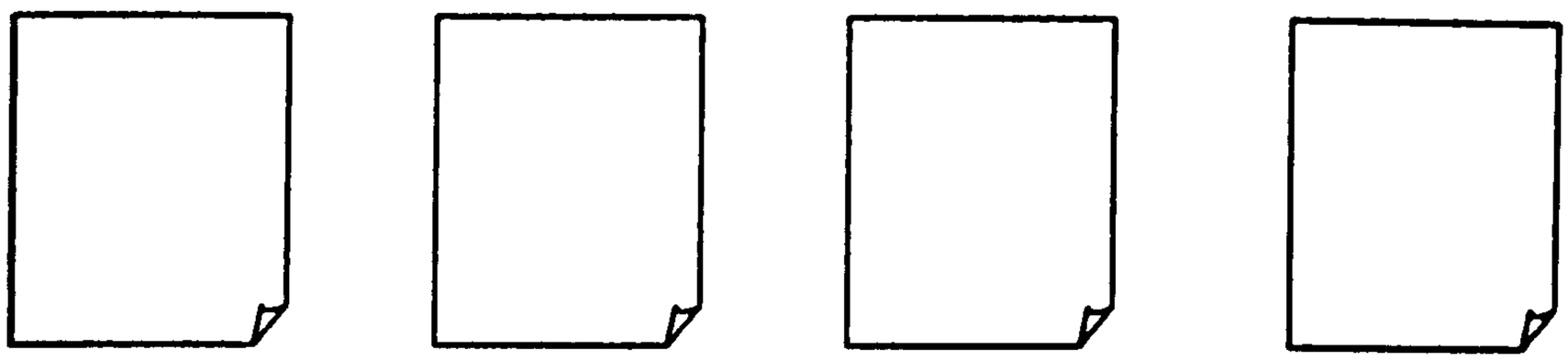
<u>Allocation of space provided on questionnaires to be used as evidence gathered by LEA in the Statementing process</u>

(a) Parents' Views



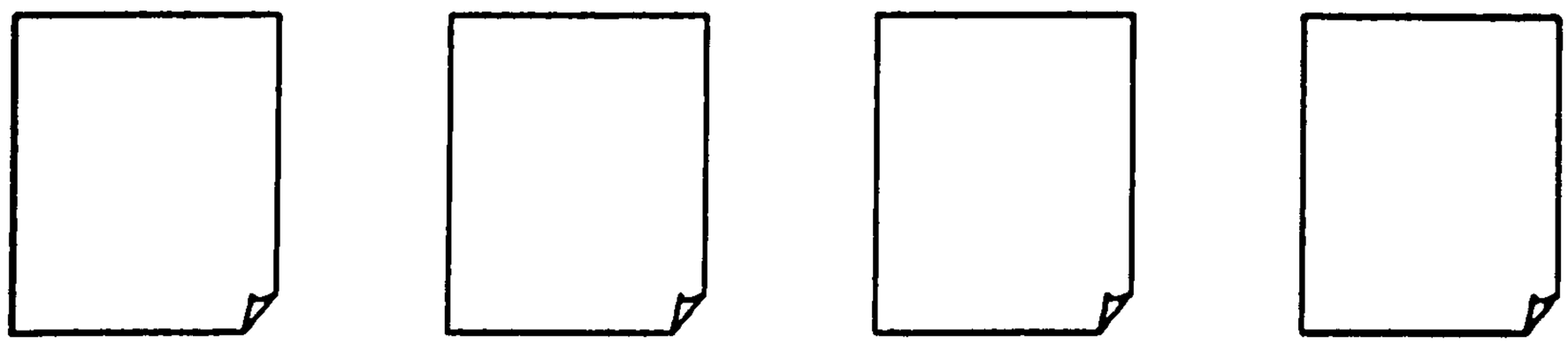
Space provided - one x A4 side of paper

(b) Medical Report completed by Consultant Community Paediatrician



Space provided - four x A4 sides of paper

(c) Psychological Advice – completed by Educational Psychologist



Space provided - five x A4 sides of paper

6.7.1.1 Objectivity versus subjective experience – the function of space provided on questionnaires

The function of the space provided is the same for all the questionnaires – to provide evidence upon which an LEA will make a decision about which programme of education is appropriate for a particular child.

In adopting 'appropriate' in this context the implication could be that the LEA would choose a programme of education (by naming a school in the Statement) which is best suited to an individual child irrespective of issues related to locality (within or outside of the LEA boundaries) and therefore funding. This implication of a value-free decision on the part of an LEA is not intended through the use of 'appropriate'.

6.7.1.2 Objectivity versus subjective experience – the construction of questionnaires

The construction of each form, however, suggests that the amount of information to be imparted will vary greatly between sources.

Two possibilities for this construction are:-

a. the LEA requires a particular type of information from each source;
b. LEAs need to base their decision of an appropriate programme of education for a child primarily on the expert evidence in the form of evidence from a community paediatrician and an educational psychologist.

The decision on whether to use capital or small letter for C(c)ommunity P(p)aediatrician and E(e)ducational P(p)sychologist is linked to the size of letter used for the other party (the P(p)arents) and as parents is a word used with a small 'p' because it does not for instance represent a title of an occupation as such, it is considered appropriate to adopt small letters for all parties. This decision is not meant to detract from or carry implications about the professional standing of the community paediatrician or the educational psychologist (bearing in mind that the debate centres around parents as equal partners). Neither is the decision intended to suggest any

analytical assumption with regard to issues of equality (as partners in the decision-making process). Instead, the small letters used for all parties is intended to represent a uniformity in presentation.

For construction (a) the assumption would be based on the notion that the parties involved are able to offer distinctly separate information on the child. In other words the community paediatrician and educational psychologist wouldn't be able to provide information supplied by parents and, similarly, parents wouldn't be able to supply information provided by the community paediatrician and educational psychologist. This could still mean that the evidence offered by all parties is equal even though one party has one A4 side of paper and the other parties four and five x A4 sides of paper and whether or not this is the case will become apparent as the analysis progresses. But, irrespective of the issue of equality in partnership the fact remains that whatever each party has to offer the parents have considerably less.

Imposing 'fact' at this stage in the investigation (or indeed at any stage in a psychological enquiry) could be problematic in terms of representation of an unquestionable account. However, as it (fact) is related to the materialistic properties and quantities of questionnaires there is no doubt that 'fact' in this sense is not incumbent upon any form of reality imposed for example on an opinion, suggestion, idea or notion.

The second possibility for the construction of space in the questionnaires (b) is that the information provided by the community paediatrician and educational psychologist is of more value in the decision-making process than the parents' perspectives. The introduction of the Code of Practice (1994) suggests that LEAs acknowledge the

importance of parental in-put into the decision-making process. The question then arises as to the possibility of the partnership representing a token partnership. (This issue will be taken up in the discussion.)

Analysis of the headings used on the questionnaires and the explanatory notes contained therein further explore the discourse of objectivity vs subjective experience.

The questions contained in the questionnaires can be reasonably expected to reflect the expectations on the type of information that LEAs expect to be forthcoming from all parties.

'Reasonably expected' in this sense could suggest that the matter (reflection of expectations) is somewhat open to debate. Although if it (the matter) cannot be reasonably expected then the alternative could be that all parties were required to answer the same questions. As this is not the case and the parties all have different questions to provide the reasonableness of expectation is considered to be an accurate assessment.

The gentler nature of the questions on the parents' views form suggests that the 'opinion' of parents is sought whereas the questions on the medical report and psychological advice could be seen to represent a factual account. Although one is based on extensive familiarity with the child (parents' views) whilst the other account is based on extensive familiarity with childhood disability and cerebral palsy and examination of the child at one point in time (community paediatrician) and observation of the child and information gathered from various sources (educational psychologist).

Analysis of the content of the questionnaires revealed the presence of the objective vs subjective experience discourse. For instance, parents are asked

"do you feel your child has difficulties? – What do you feel they are?"

whereas the Medical report asks for

"Past medical history – of relevance to the child's special educational needs."

and educational psychologist is required to provide

"Any relevant background information"

The opinion of parents is sought through their subjective experience represented by "do you feel" whereas the community paediatrician and educational psychologist are not asked for their 'feelings' but for a factual account.

The use of 'difficulties' in this context suggests that the LEA consider reference to 'disability' to be inappropriate when canvassing parents. There are two possibilities for this:

a. non-reference means non-existence i.e. invisibility of disability, or
b. that LEAs consider the term 'disability' to reside in the domain of the expert and therefore the ownership of 'disability' and related issues resides with the experts.

This issue is explored further by consideration of the assistance LEAs offer in answering questions. For parents, the help is in the form of

"Do you feel your child has difficulties? What do you feel they are? You may wish to say what he is like at home or in other places or whether there are any medical difficulties, for example."

Here the 'difficulties' are those which are experienced 'in the home' where the parents mostly observe their child or 'in other places' which suggests that parents are able to extend their observations outside of the 'home' but these will still relate to their feelings – 'what do you feel they are.' In this sense the inference is that parents are unable to offer factual information – their 'feelings' will be open to interpretation. However, parents are also offered, through the explanatory note, to comment on "medical difficulties". The linking of these two words could be considered somewhat ambivalent because 'medical' suggests facts whereas the term 'difficulties' again suggests that parents are removed from the factual terminology that 'disability' could suggest.

An assumption is made that 'medical' represents 'fact' and this is mostly drawn from a familiarity with the analysis as a whole rather than the analysis so far which would not necessarily offer enough justification for this assumption.

> "What has been tried so far? If your child has had any special help either at home or at school, you may wish to mention it here."

The issue of 'what has been tried so far' is taken up in the negativity vs positivity discourse but of specific relevance to this discourse is

> 'you may wish to mention here.'

The delicate nature of the terminology of "wish"[ing] to "mention" suggests that there may be issues which the parents would like to include but that their inclusion is not essential for the purpose of providing evidence, rather that this is the place to do so if the need (wish) should arise. The issues themselves are related to 'special help either at home or at school.' Perhaps of particular note is the exclusion of a discourse with

regard to support or programme although parents are considered appropriately qualified to comment on these issues in the school environment as well as the home, but only in relation to 'special help'.

The next explanatory note accompanying a question illustrates clearly the LEAs expectations of parents as form-fillers.

> "What might be useful in the future? Here you can tell me what you think would help your child in the future."

The sensitivity and personal issues of construction are greatly extended throughout the sentences intended to assist parents with their questions "you may wish", "here you can tell me" and "what you think".

But the explanatory notes in this instance are so similar to the question itself that its function is one of re-iteration. The opportunity for alternative constructions is therefore limited – there are no further indications of the type of information expected other than 'useful' being elaborated by 'what you think would help' and 'what might be' is further explained through 'here you can tell me.'

There is an element here which suggests that specificity is undervalued with the opportunity for parents, who can be specific across time, being missed.

The community paediatrician is asked for

> "recommendations, implications and advice"

Interestingly, the medical report states that

"In all areas, indicate if statements based on direct exam or report

by the parent or others."

This would seem to have a bearing on the factual nature of the account. It suggests that the source of the information is as important as the information itself.

This final interpretation returns the argument to the 'truth' accorded to each piece of information.

This tends to take the discourse beyond that of objectivity vs subjective experience (with one discourse being based on fact and the other on opinion) to the theoretical implications of parents as informed decision-makers and this is taken up in the discussion.

The equivalent questions in the medical report and psychological advice could be considered to be worded to elicit fact. Looking at the questions alongside each other for instance, parents' are asked to comment on

"What is your child good at? Does your child make friends easily?

Has your child any special interests?"

The medical report equivalent asks for information on

"Social behavioural and emotional development (including self-help skills)".

And educational psychologist's report

"child's skills and attainments"

The construction differential here suggests that the experts in the form of community paediatrician and educational psychologist are removed from the situation whereas the parents are close to the situation and therefore the alternative report-style terminology would be too blunt for parents. This sensitivity demonstrated by the LEA could be applauded except that it underlines the non-equal status of the parents with the experts by taking the sensitivity and personal issues so far that they cross over into the condescending.

'Condescending' in this sense is tested for its correct usage against one of the question to parents "what might be useful in the future? Here you can tell me what you think would help your child in the future." Is this an example of sensitivity or condescension.

One of the most revealing observations is that the medical report is mostly seeking facts whilst the parents' views represent a much softer, gentler approach with a personal touch. This could mean that the community paediatrician and educational psychologist can be expected to be objective whilst the parents who are providing information on their child will have to limit their facts to what they 'feel'. Also, whilst the practitioner represents the medical profession, the information provided should be 'relevant to the child's special educational needs' and also contain 'additional comments and implications for education.' This suggests that an expert can extend expertise across fields whilst a parent must remain in one domain. The medical report covers all questions related to past medical history and current physical health - vision, hearing, speech, language and motor function. The report of the educational psychologist is also detailed in this respect. The parent is required to record 'difficulties.' 'The medical

report questions do not offer any additional explanation whereas the parents' views are spelled out almost in the style of treading on egg shells and/or perhaps making the disability invisible.

A further illustration on the nature of the information expected from each source (factual or opinion-based) refers to the

"child's skills and attainments"

in the educational psychologist's advice. The LEA explanatory notes on this question require

"....and the actual performance of the child (e.g. on standardised tests)."

As parents are not required to provide an account of their child's 'actual performance' it can be deduced that a measure of 'truth' is allocated to a child's performance on standardised tests if these are provided by the educational psychologist.

Whilst endeavouring to maintain the anonymity of the parents involved in this investigation it is extremely relevant to state that the parents attached 3 x A4 sides of paper to their questionnaire as supplementary information which included all aspects of their child's abilities, physically, cognitively and socially. Contained in this supplementary information (but not directly quoted here) is the concern that the child's performance often depends on context to the extent that an artificial test situation does not always elicit an accurate account of a measure of ability.

The next source from which illustrations of the objectivity vs subjective experience discourse are drawn is the LEA Statement itself. Exploration of this documentation

revealed the extent to which evidence from three sources (already discussed) is included in the LEA Statement.

Of the 5 x A4 sides provided by the educational psychologist, the 4 x A4 sides provided by the community paediatrician and the one x A4 side provided by the parents (together with 3 x A4 sides of supplementary information) the majority of information contained in the Statement is taken from the psychological advice prepared by the educational psychologist from the council's education department. There are items from the medical report included and also from parents' views (already included in the psychological advice). However, some of the items raised in the parents' supplementary information refer to issues which the parents consider could only be addressed through enrolment on a programme of Conductive Education – none of these items are included in the LEA Statement and this will be taken up in the discussion.

It would have been useful to illustrate the point on items specifically related to Conductive Education in order to remove the possibility of researcher-bias but issues of anonymity prevent this and the possibility of researcher-bias is addressed by reiterating a point made earlier. This point is that the analysis represents one interpretation and that this interpretation carries with it the values brought to it by one researcher and that these values are intended to represent a strength.

The final source for analysis of the objectivity vs subjective experience discourse are the guidelines which parents receive when they are not in agreement with their LEA Statement and appeal against the decision through a tribunal hearing – tribunal guidelines.

This badly-reproduced form (Appendix IV) is headed 'Parent' and sets out the procedure that parents can expect when presenting their case to the Tribunal.

That the form is badly-reproduced appears to have a bearing on the form itself. It suggests a type of unprofessionalism on the part of the tribunal services which appears to be directed towards the receivers of the form – the parents. And yet the issue which is central to this investigation – are parents equal partners in the decision-making process – centres around discourses of facts and opinions of which professionalism (or non-professionalism) could be a part. The debate is concerned with experts as professionals and parents as non-professionals so a non-professionally reproduced form could be evidence towards the debate. This could have been the case except that the non-professionalism of the form has been imposed upon it by the researcher through its badly-reproduced condition. Non-professionalism is only an issue if the assumption that it is represented by bad reproduction is accepted.

Analysis first of all suggests that a party/parties other than 'Parent' also receive guidelines for this procedure – because of the heading.

The following extract strongly suggests that the guidelines (if any) that other parties receive will not contain the same terminology. This assumptions is based on familiarity with the type of terminology used for different parties thus far as well as the technique of deduction. Parents are advised that

> "Taking each aspect of the case in turn will give everyone the opportunity to concentrate on points as they come up, without

getting muddled."

Analysis primarily through deduction could be problematic in terms of validation but in this instance it would be difficult to imagine a situation where the guidelines to parties other than 'parent' were provided to avoid the part "getting muddled".

Also, the recognition by the writers of the guidelines that parents might get 'muddled' suggests (by the recognition) an expectation of the possibility, as well as a superiority effect – knowledge of the possibility removes the writers themselves from the category of persons who may become 'muddled'.

A further incidence of the same discourse within the same document is

"It may be a good idea to make a list, in advance, of what you would like the tribunal to consider. You can then tick the matters off as they are discussed, and at the end bring up any which were left out."

This objectivity vs subjective experience discourse in operation here suggests that parents, irrespective of academic achievement or occupation, would not be able to transfer any of their previously learned skills to a situation of this nature and the construction of this discourse is to make clear the procedural issues involved. The function of the guidelines is

to prevent parents becoming 'muddled'

whilst the construction represents a hierarchy of procedural knowledge.

6.7.2 The discourse of negativity versus positivity

The central theme to this discourse is based on a concentration, by the agencies involved, on the 'limitations' rather than 'abilities' of a child. An illustration of a negative discourse in operation appears in the questionnaire for parents which asks

"Do you feel your child has difficulties"

The 'you feel' and 'difficulties' issues have already been analysed in the objectivity vs subjective experience discourse. For this discourse the whole question centres on what a child cannot do. However, this is balanced by a positive discourse in the same questionnaire

"what is your child good at"

Without reference to the explanatory notes these two questions could represent two sides of a coin. Allowing for the 'difficulties' terminology already discussed, one question is intended to elicit information on a child's limitations whereas the other is concerned with a child's abilities (what the child is able to do) which is recognised through the outcome of being 'good' at. This suggests that the LEA is interested in parents' opinions ("do you feel") on 'difficulties' and 'good at' in the same way as the educational psychologist is asked for information on

"factors which may have affected the child's progress and development" and

"child's skills and attainments"

However, analysis of the explanatory notes on questions to parents suggests that the construction of the questions is such that the type of information required (or expected) from parents is different from that required from the educational psychologist and that the difference is not based solely on fact vs opinion. The explanatory notes of "what is your child good at" are

"Does your child make friends easily?" and

"Has your child any special interests?"

This discourse moves parents outside the medical and educational domains of information-providers. Parents are considered by the LEA to be appropriate information-givers on issues of a social-behavioural nature and yet, as already stated, the supplementary information provided by these parents contains detailed information on the specific physical, cognitive and social abilities of their child.

Issues of a social-behavioural nature may not be considered to be appropriately linked to "do you feel your child has difficulties" and "what is your child good at" except as these relate to the explanatory notes of "does your child make friends easily" and "has your child any special interests." The applicability of this term (social-behavioural) is only present when the question and the explanatory notes are considered as a whole rather than as separate items.

Another illustration of the positivity vs negativity discourse in operation is from the LEA statement and this also crosses over into the discourse on 'normalisation.'

"In comparison to the majority of pupils of [child]'s age..."

The function of this sentence as a whole is to provide a measurement of difference upon which an assessment is based whereas the construction suggests the measurement as justification for the information which is to follow (the choice of a programme of education) through identification of the appropriate school.

The measurement of difference to the "majority of pupils" wholeheartedly enters the negativity discourse on how the child measures up to what other children are able to do and this issue is taken up in the discussion.

Another illustration, representing the negativity discourse and based on the assumption of failure is found in the parents' questionnaire

"What has been tried so far"

Which ignores the possibility of 'what has been successful so far' thereby suggesting that the ideal 'what' has not yet been found. This discourse also underlines the existence of a problem or the expectation that parents would not be able to assess the success or failure of 'what' and therefore everything that has been 'tried' would need to appear in one category of 'trying'.

The existence of a problem, with respect to the past tense of 'tried', represents either a problem that has not yet been solved or a problem that is not able to be solved. The problem is derived therefore not merely from the 'what' but from the 'tried', rather than 'trying' sense of the 'what'.

6.7.3 The discourse of current disability versus potential ability

The discourse surrounding current disability vs potential ability is at the centre of the disparity between what the LEA consider to be the appropriate programme of education and what parents consider to be appropriate to meet their child's needs.

The psychological advice upon which the majority of the LEA statement is based includes many elements of the child's ability as well as suggestions for educational provision to meet future needs and these are concerned with

Curriculum

Facilities and equipment

Human resources and support services

Group size

Attendance

These are seen by the educational psychologist as separate issues and to some extent based on the child's current disability

"equipment necessary to cater for [child]'s physical difficulties."

In other words the child's current disability is facilitated through equipment to meet current needs.

Although provision is also recognised for

"frequent monitoring of individual programmes"

which suggests that the individual programmes will not remain static.

The opportunity provided to parents to comment on their child's potential ability on the questionnaire is in answering a question on

"what might be useful in the future"

The LEA do not offer any assistance in answering this question. The explanatory note (already discussed) serves to re-iterate the question "Here you can tell me what you think would help your child in the future". The broadness of this question and the ineffectiveness of the explanatory note suggest that parents have a free hand in deciding what to answer here although it is possible that "a six-month holiday abroad" may not be an expected answer.

This is an extreme example of the broadness of the question and is not intended to represent any expectation on the part of the LEA. Any suggestion of such an expectation would itself represent a somewhat ludicrous view of the LEA which is not intended.

The answer given by the parents relates to the encouragement of independence and this is further expanded in the supplementary information (anonymity maintained through the sense of the text being presented rather than the exact words). Parents express concern that their child will be a passive receiver of a programme of education rather than an active participant. An environment suited to their child's current disability is regarded by the parents as inappropriate.

Illustrations of a discourse in operation without the use of the exact text could be considered to be problematic as the evidence of the analysis is not available to the reader. The exact text, however, could identify the parents and the child and this issue takes priority over researcher interpretation (which has already been discussed.)

However, the LEA Statement, whilst containing elements which suggest awareness of the importance of maximising potential ability

"....short and long-term targets to be set by the school in consultation with

[child]'s parents"

issues of physical and cognitive abilities are seen as separate issues although the specific nature of these prevents illustration for reasons of maintaining anonymity.

6.8 Theoretical implications identified

Analysis of the three discourses, objectivity vs subjective experience, negativity vs positivity and current disability vs potential ability form the basis from which the theoretical implications emerge.

There are two major theoretical implications and these are both concerned with a disparity which exists between LEAs and parents with regard to the decision-making process. The implications are:-

- parents' decisions are ill-informed and/or under-valued
- the provision of a programme of education represents different fundamental underpinnings for both parties

A framework of the theoretical implications is set out before their discussion in full in the next section.

6.8.1 The theoretical framework

DISPARITY BETWEEN LEA & PARENTS

Evidenced by different decisions on choice of educational programme

Possible causes

Parents' decisions

|

Ill-informed
And/or under-valued

|

linked to

Allocation of truth

Fundamental Underpinnings

of a programme of ed.

|

linked to

Transcendence of fields
From medic to educator

Figure .10.

6.9 Theoretical implications discussed

The disparity between the two parties (LEA and parents) is evidenced by the need for a tribunal hearing caused by the non-agreement between the parties on the most appropriate provision of a programme of education for one child with cerebral palsy.

The possibilities for this disparity are that

a. parents' decisions are ill-informed and that the LEA's decision is informed and/or parents, as partners in the decision-making process, have opinions that are under-valued (and allocation of truth)
b. that the provision of a programme of education represents different fundamental underpinnings for both parties (and transcendence of fields)

In discussing these theoretical implications two further sources of documentation which represent one interpretation of expert opinion are drawn upon as evidence in this field. The first source is an editorial by Bax, M. (1993) which reports on a meeting to launch the Bairstow et al (1993) report at the collaborating Institute (Appendix II). The second sources (but same author), written five years later, also offers further evidence with regard to the discourses involved (Appendix III).

The detailed relevance of this documentation is set out both in chapter five and earlier in this chapter. Briefly, the relevance of Bax (1993) is due to the fact that the Baristow et al (1993) report discussed by Bax concerns a 5-year government funded investigation carried out at the collaborating Institute for this study. Bax (1998) offers a more recent interpretation of one expert's views on parents as equal partners in the decision-making process. Evidence from this documentation is interwoven into the discussion of this part of the investigation.

6.9.1 Parents as ill-informed partners and/or parents as under-valued partners

The amount of space that the LEA provides for parents to contribute to the decision-making process is considerably less than the other two sources. This means that whatever each party has to offer, parents are deemed to have less. This suggests, at the very least, that the specificity parents are able to offer is under-valued by the LEA.

Also, the terminology used in the questions and the explanatory notes on all questionnaires suggest that all parties will be able to offer different information. There appear to be two types of terminology used – one is gentle and requires the expression of opinion related to feelings (the parents) and the other is direct and requires factual information (community paediatrician and educational psychologist).

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There could be two reasons for this. One is that the LEAs consider it more appropriate to elicit opinion from the source with subjective experience – parents who are familiar with their individual child across time – and experts who are able to offer an objective account of an individual based on their knowledge of childhood disability and education. The other possibility is that the LEA consider the experts to have entered the culture of childhood disability and education whilst they believe the parents to be outside the culture.

To grasp the differential which exists between the expectations of opinion or fact from each party, by the LEA, as well as to gain an understanding of the construction of the forms, it is useful to consider a hypothetical situation. Imagine that each party received the wrong form - the parents were requested to complete the medical report or the psychological advice and the community paediatrician and educational psychologist were asked to complete the parents' views forms.

This hypothetical situation tends to highlight the factual nature of the one form and the opinion-basis of the other. The personal nature of the parents' questionnaire "you may wish to" or "what do you feel" would also appear to be inappropriate for the community paediatrician or the educational psychologist. Although the value of the form comes across through this personal context suggesting that the LEA is keen to know the opinion of the form-filler but also emphasises to some extent that this will not be as factual as the medical report. So, to imagine the community paediatrician or educational psychologist completing the parents' views form is nothing more than a little odd. The terminology used "difficulties" and "good at" instead of perhaps

"disabilities" and "ability" suggesting a certain sensitivity to the party filling in this form or the inability of the party to comment on matters of 'disability' or 'ability'.

Now imagine the parents completing the medical report or the psychological advice. Evidence that this would not be too insensitive in terminology comes from the fact that these parents attached three sheets of A4 paper as additional information which contained background information, current limitations and ability, future expectations, self-help skills, social relationships and future educational needs.

So, parents could complete the medical report or the psychological advice but of how much value would this be. If for instance both parties were required to fill a comprehensive questionnaire on 'Past Medical History', 'Physical Health' and 'Social Behaviour and emotional development' and the parties didn't agree on the content then which information would the LEA include in the statement. This hypothetical situation tends to highlight the differential which exists with regard to the expectations of the form-filler by the LEA. The analysis suggests that expert opinion is valued more than parents' views.

Expert opinion in this sense is not intended to shift the debate from experts providing factual accounts and parents providing opinions but instead to represent expert's views. Opinion in this context is used therefore in the sense of one side (rather than the other) as an account with no bearing on the term 'opinion' as it is used elsewhere in the analysis.

Further discussion provides evidence of whether (or not) this issue of the undervaluing of parents' views is only present in the hypothetical situation.

Perhaps the amount and type of information the parents had to offer is of no consequence if the final Statement is to be based on what the LEA consider to be a factual account from the community paediatrician and educational psychologist. The amount of information supplied by parents that the LEA include in their Statement suggests this. Further evidence of opinion not given as much value as fact is found in Bax (1993) when commenting on the launch of the Bairstow, Cochrane & Hur (1993) report on Conductive Education at the collaborating Institute.

The author did not see the meeting as profitable because some parents "...strongly felt that the method [Conductive Education] *had* benefited their child" (p.659) and yet the conclusions from the 5 year government-funded report are that there were no differences between Conductive Education and a comparison group.

Deductively this suggests that the meeting would only have been profitable if the parents had agreed with the conclusions – based as they were on scientific enquiry. This evidence suggests that there is a measure of 'truth' that is allocated to experts (as researchers of a scientific investigation) that is not awarded to parents as service-users of Conductive Education. The 'had' in italics suggests some incredulity on the part of the author because of the parents' non-agreement with the findings. The implication that parents' opinions are ill-informed and under-valued is further evidenced by Bax who states "..... it is always puzzling for parents as to why we professionals do not take their word for this [that Conductive Education *had* benefited their child]". The main

point here is that the 'this' is of no relevance – it could be a Bach remedy or a programme of education (Appendix II) but if there is no scientific proof of its superiority then the professionals will not include it in their repertoire and will therefore not endorse it or recommend it. But there is also another important point and this relates to 'we professionals'. This term used in this context endorses an earlier point with regard to the culture of childhood disability and education. It seems that 'we professionals' is a body of experts who reside in the same domain and that the parents are not a part of this body and do not occupy the same culture.

A more recent view of the author Bax (1998) also confirms one experts' opinion about the value of the subjective experience of parents

"..find it difficult to be objective in evaluating information about treatment"

There are several occasions in the two publications when 'therapy', 'treatment' and 'education' appear in the same category and this issue is discussed next. The point of this illustration, as evidence, is that parents are not in a position to be objective and, deductively, if they cannot be objective they cannot evaluate. Objectivity in this sense is the only acceptable criteria – subjective experience is not under-valued **it is of no value.**

Reference to this documentation appears to confirm the implication that the amount to which the decision-making process for parents is based on an informed view is of no consequence. Informed or ill-informed, parents' opinions are based on subjective experience and are therefore of no value in comparison to the evidence based on objective expertise.

The issue of the inferiority of subjective experience which occurs in the analysis when parents are expected to become 'muddled' (Appendix IV) is evidenced further by Bax (1998) commenting on parents' preferences

"have benefited their child enormously. This is good, and, to any parent who feels that a particular type of therapy is helping their child, the sensible advice – provided one is happy that the child is not actually being harmed – is for them to pursue that course of treatment" (p. 507).

Here, parents are afforded preferences but the ultimate ownership must rest with the professional. The discourse that is absent from this text serves to highlight the superiority of the expert opinion. There is no suggestion that parents' opinions may be correct – the implication is that parents are allowed to have feelings that their child has 'benefited enormously' but these feelings are valued to the extent that 'provided one is happy the child is not actually being harmed.'

6.9.2 Perspectives on the fundamental underpinnings of a programme of education

The discourses of negativity vs positivity and current disability vs potential ability in particular relate to this theoretical implication – that the disparity which exists between LEAs and parents is caused by the differential of each party on the fundamental underpinnings of a programme of education.

Exploration through the application of discourse analysis revealed that the statement produced by the LEA is based upon a child's current disability with short and long-term targets focussed on issues which separate the physical, cognitive and social objectives

into discreet categories. In other words a programme of education, from the perspectives of the LEA, will reflect a child's current disability through modifications to the teaching environment and teaching practice and potential ability through short and long-term objectives. Each area will be monitored frequently and parents consulted about the programme. Maximisation of potential ability, in this sense, could be seen to be a priority of the LEA. In this sense the child's potential ability is maximised through the meeting of objectives.

But the LEA view aspects of physical skills, speech and language skills requiring specialist input as issues of a non-educational nature. So, the educational needs and non-educational needs will be met through the delivery of these components from appropriate personnel and/or specialists. The child will be a recipient of these services.

The LEA also believe that experts outside of education are able to extend their expertise to matters of education for children with cerebral palsy. This is borne out by the questions the LEA ask the community paediatrician

"Past medical history – of relevance to the child's Special Educational Needs" and

"Additional comments and implications for education."

So, the community paediatrician, although not qualified in the education sector, provides information of a medical nature which could have a bearing on the type of education provision for a child. This confirms the notion that elements of the child's education are seen by the LEA as discreet – unless the community paediatrician is expected to comment on the national curriculum this has to be the case.

Although not seen elsewhere in investigations the technique of hypothetically testing appears useful in clarifying certain obscure points and will be applied once again – and for the last time in case it would lose its appeal (if any) through over-usage.

Imagine a situation where the consultant community paediatrician is (or of the same mind as) the author of the recently-discussed documentation – Bax (1993, 1998) who is indeed a consultant paediatrician. If this were the case then it is possible that the question on

"Additional comments and implications for education"

would highlight the disparity between LEAs and parents and primarily through the views of Bax, M. on a non-traditional programme of education having an outlet such as this question. To explain and illustrate this point further it is necessary to cross over (as discourse analysis often has to) into the area of objectivity vs subjective experience.

It has already been established that the LEA values expert opinion (evidenced by the space provided on questionnaires, the type of information required and the amount included in the LEA statement) and that expert opinion is considered to be objectively-based on fact. So in this hypothetical situation it could be deduced that Bax would objectively answer

"additional comments and implications for education"

based on fact and not opinion. However, further exploration of Bax (1993) suggests this may not be the case. A major statement on Conductive Education appears to be based on fact

"It is hard to know whether Dr. Har[t]i from Budapest or Andrew S[sc]utton, representing the Institute of Conductive Education in the UK really believes that if a

further study were carried out or pursued longer a more positive result for conductive education would emerge. It seems to me unlikely."

Here, Bax has extended his opinion "It seems to me unlikely" to that of others "It is hard to know whether..." but the two major points come from the implications of the whole sentence. Firstly more positive results (than no differences) are not expected, by others, in the future. Secondly that as consultant paediatrician Bax is in a position to advice parents and inform a wide audience through non-refereed editorials.

To focus on the relevance of the foregoing to the possibility of the disparity being caused by fundamental differences, Bax says

"....in the real world run by governments services for children with disabilities are hard even to maintain, let alone develop..."

In this sense it could reasonably be deduced that to 'maintain' refers to existing systems whereas 'develop' relates to new systems (in 1993) in which case the differences between the fundamental underpinnings are no longer of primary importance. The implication is that it matters not whether a new system is proven, scientifically, to be superior to existing systems (nor whether existing systems are appropriate) – there is no money available to develop new systems only enough to maintain existing ones.

However, it appears that subjective experience is not under-valued by all those concerned with providing education for children with cerebral palsy. Andrew Sutton, the professional Director at the collaborating Institute, himself an Educational psychologist in the U.K. prior to 1987, heard about Conductive Education in the

1970s, listened to the opinions of parents who had visited the Peto Institute , visited there himself and eventually forged a partnership between Birmingham and Hungary to bring Conductive Education to this country.

So, the value of subjective experience by a handful of people resulted in the introduction and development of Conductive Education in the UK over the past 12 years. As Heather (1976) suggests, positivism dictates simplicity in the experimental setting so that unequivocal conclusions may be drawn. But these pioneers operated on the understanding that action and meaning are tied to particular contexts and cannot be understood from an external or objective standpoint as suggested by Layder (1994) and set out in Chapter two of this investigation.

In this sense, a science of children and education will be a science that is truly reflexive and will therefore not attempt the transportation of Conductive Education from Hungary to the United Kingdom without certain adaptations to reflect the different context. However, analysis of the construction of the documentation and supporting evidence suggests a type of subordination in the role parents have as decision-makers.

This construction feeds into itself and also represents the major implications. In other words, if parents are portrayed by their partners (LEAs) in the decision-making process as subordinate then it could become acceptable for their opinions to be perceived as ill-informed and subsequently under-valued. Ill-informed in the sense that they base their decision on subjective factors unrelated to their children's needs and under-valued because their perceptions of the disparity existing between a programme of Conductive Education and local education authority provision, on a fundamental basis, are ignored.

6.10 Summary

To summarise, two major theoretical implications are explored through the application of discourse analysis – parents as ill-informed and/or under-valued partners and the disparity on the perspectives of the fundamental underpinnings of an appropriate programme of education between the two parties. These issues are discussed and the conclusions drawn on the construction of the discourse suggest that parents are portrayed as subordinate in the partnership and their subjective experiences are ignored.

These major themes are further explored in the next chapter – Chapter seven – when the findings from each of the methodologies are brought together for discussion.

Chapter Seven: Conclusions and Reflections

This chapter brings together the findings from chapters five and six. The major theoretical implications are discussed and reflected upon in terms of the conclusions drawn, the appropriateness of the methodologies applied and the position of the researcher in undertaking this thesis.

7.1 Introduction

There have been two major aims in this investigation:

- To explore parents' perceptions on a programme of Conductive Education (in this sense 'perceptions' is intended to represent parents' 'understanding' rather than to imply 'intuitive judgement');
- To identify how parents make sense of their decision-making process with regard To enrolment on a programme of education.

In chapter five, interview data were analysed through the application of the grounded theory method of enquiry. The major implications emerging suggested that parents' perceptions of a programme of Conductive Education as practised at the National Institute in Birmingham, reflect their understanding of the differences that exist between the fundamental underpinnings of their chosen programme and a traditional programme of special education. The second major implication in chapter five suggests that parents perceive their choices to be considered, by LEAs, to be ill-informed and therefore under-valued.

These two major implications are explored further in chapter six by first of all identification of the discourses in operation in the text and secondly by seeking further

evidence of their presence. The identification of the discourses is concerned with parents' perceptions of the position of LEAs in the decision-making process as well as the particular relevance to the major implications which emerged in chapter five. Further exploration of the implications through the application of discourse analysis on the three discourses involved (negativity vs positivity, current disability vs potential ability and objectivity vs subjective experience) further support the idea that parents are considered by LEAs to be subordinate partners in the decision-making process and their subjective experiences are ignored.

7.2 Aims

The final element of enquiry, aims to pinpoint the major theoretical implications that are considered to be pivotal to the enquiry as a whole. This, the third angle, aims to get a 'fix' (Robson, 1993, p.290) on the central themes from the knowledge of the findings through both methodologies to offer an interpretation of 'what is happening'.

7.3 The Construction

7.3.1 - Of Childhood and Parenthood

An outline of what is meant by the construction of childhood and parenthood in general sets the scene for their specific relevance to the context of this investigation.

The existence of the delineation of childhood is constructed through its relationship to other (supposedly distinct) stages of the lifespan. In this respect, "The child exists in relation to the category 'adult'" (Burman, 1994, p. 48). The notion of the child as powerless, in a state of 'childhood' which is regulated by agencies, has been traced historically (Dingwall, Eekelaar and Murray, 1984; Hunt, 1985; Hendrick, 1990 and Hoyles, 1989). The concept of the existence of discrete stages constructed through relationships to other stages is clearly seen with regard to parenthood. Parenthood

exists in relation to the category of 'child' although, in a sense, the construction of parenthood is directly related to that of childhood because without the one, the other would not exist. In other words, parenthood is not so much a distinct stage which only becomes apparent when measured against other categories such as 'childhood' or 'adulthood'; parenthood exists *alongside* childhood. This being the case, the issues which represent the construction of childhood will also impact upon parenthood.

For this investigation the relevance of the construction of childhood and parenthood lay in the notion of the construction of a universal childhood (and hence a universal parenthood). Specifically with regard to education in general this means that a universal ideal of childhood is constructed through mass schooling which is regulated and surveyed by the national curriculum (Hunt, 1985). The ideal child will be the conforming child. However, it is not only the agencies that monitor the uneducated child through the transition to the universal child. Parents are also a part of this regulating process *if* they embrace the notion of universal parenthood – conformity, acceptance and encouragement towards the ideal construction of childhood through mass schooling and the constraints of the national curriculum.

The findings from chapters five and six of this study suggest that the agencies involved do not believe that these parents choose Conductive Education, as it is practised at the National Institute in Birmingham, because it is the most suitable programme of education to meet the needs of their child. The agencies involved are in non-agreement with the parents because the parents do not conform to the *ideals* of the universal parent and universal childhood.

7.3.2 - Of Disability

Parents of this investigation perceive that their child's disability is socially constructed. According to parents, the *dis*ability of their child is seen by 'experts' as the limiting factor which prevents the children from fitting into the able-bodied life-style of their peers. Parents believe the focus of 'experts' to be on a disability – cerebral palsy – which has been categorised to represent its limiting factors through the measurement of inability in two ways. Firstly against able-bodiedness and secondly alongside cerebral-palsiedness. These two measurements are seen, by parents, to represent a construction of their child's disability which has been socially constructed by the measurements themselves. In this sense, the measurements themselves are the tools of construction.

7.3.3 - Of Identity

Recognition by parents that their child's identity is socially constructed is represented by the central theme in Chapter Five – the orchestration of identity. Their child's actual self-hood is impacted upon by the type of programme of education they are exposed to. With the findings of both angles of enquiry to hand there appear to be two representations of identity – one that is fixed and never changing and the other that is absorbent and in a constant state of change and these are discussed individually.

7.3.3.1 Identity as Fixed

Parents perceive a programme of education which is based on a child's disability as representative of an expectation that there will be no changes in the child's identity. In this sense if a child with cerebral palsy has a motor impairment then this child will always have a motor impairment and the level of severity (for want of a better word) will remain the same. If a child has a non-motoric impairment which affects speech, then an alternative means of communication, such as symbolic communication, will be

introduced as an alternative to speech – the child doesn't speak so the child won't speak. These parents perceive LEA special education provision to represent a programme of education which 'fixes' a child's identity to one point in time.

7.3.3.2 The Absorbent Identity

Parents, on the other hand, do not view the identity of their child as a fixed entity. For parents the identity of their child is never static but always changing and not dependent upon limitations as represented by disability. For parents, motoric and non-motoric impairments do not define a child's current and future identity because they are open to change. Negative attitudes to ability are seen by parents as representing a re-enforcement of inability which located limitations in a disability that is fixed and non-absorbent.

7.4 Pathologizing education

Perceptions of parents on Conductive Education and, the rationale adopted by parents in terms of how they make sense of their decision-making process, have been identified and explored in-depth. However this sense-making can only apply to these parents with regard to how they make sense of deciding to choose Conductive Education. This is not meant to represent a repetition of points made earlier with regard to the limitations of the study i.e. that the findings are relevant to these participants at this particular point in time. The concept not yet discussed is that parents' sense-making refers only to Conductive Education because they *cannot* make sense of what, to them, is the alternative – a traditional programme of special education – because, to these parents, it does not make sense. It does not make sense because it has been pathologised; the decision on an appropriate site for education to take place rests on the

identification of the limitations of a child. The theoretical implications associated with pathologizing education are divided into two parts. The first is based on the position that special needs education, in the traditional sense of the words, is pathologized *through* 'appropriateness'. The second implication is that the pathologizing of 'appropriateness' by agencies involved, moves beyond covert regulation (Billington, 1996) to overt control.

7.4.1 Pathologizing education through 'appropriateness'

To understand the theoretical implications with regard to Conductive Education specifically it is relevant to look at traditional programmes of special education for two reasons. Firstly, because traditional programmes of special education are what Conductive Education has been measured against in the past, and hence is therefore where the 'alternativeness' of Conductive Education can be found. Secondly, if the context of special needs education is to inform our understanding (and lay bare the theoretical underpinnings) then it is from traditional programmes in the U.K. that this will be found rather than the context, historically, of Conductive Education in Hungary.

For this investigation the historical context is that a traditional programme of special Education is determined by matching each individual child to a school which is considered, by the LEA, to be 'appropriate' to meet the needs of a child. The first point to make is that the 'appropriateness' refers to a school and not a programme of education, and this point becomes clearer as the criteria of 'appropriateness' is considered. The first criteria for this match is for the LEA to identify a child's physical limitations so that a school with facilities to accommodate the limitations may be matched to the child. The second point is that although LEA special education

provision, as the very name suggests, is designed to deliver the national curriculum to children with disabilities, this is done through mimicking the national curriculum set up for able-bodied children. The basic assumption is - they are children so they must be educated through existing ideas of what constitutes 'education'; they are disabled so the programme of education for able-bodied children will be adapted to accommodate the disabilities. In the case of children with disabilities this means that the more disabled the child, the less national curriculum they receive. Insight gained from a visit to an LEA special education school (as an orienteering exercise) exemplifies this point. A French lesson was taking place in a class of children with a wide range of physical and non-motoric disabilities. Some children had been baking bread to represent the eating habits in France. The teacher explained that those children who were not able to participate in the bread-making exercise would, nevertheless, experience the French lesson - because they could smell the bread.

'Appropriateness' in this sense could vary from keeping disabled children off the streets, out of their parents' hair, away from able-bodied peers, habilitated, educated or smelling their way through the national curriculum.

7.4.2 Pathologizing education: from covert regulation to overt control

LEAs shift from a covert regulation of childhood education to overt control primarily as a result of parents non-conformity with existing procedures of enrolment on traditional programmes of education. Any decision-making partnership which existed at the beginning of the process is terminated when parents do not choose an LEA special education school. When the aspirations of parents do not co-incide with aspirations of agencies, parents become powerless. The process of educational

provision for children with special needs perhaps in itself masks the control that agencies have over families. It is possible that the "soul of the young citizen has become the object of government through expertise" (Rose, 1989: p.131) is never more the case than in the context of childhood disability.

Those parents who choose what, to local authorities, is an alternative programme of education – Conductive Education – are representative of what Foucault refers to as a bio-power. By normalising traditional programmes of education for children with cerebral palsy, authorities create deviations and perversions of education out of those that they exclude (Layder, 1994) and this in turn creates a sort of strength of validity in the case presented by local education authorities in the decision-making process.

In connection with parents of this study, this shift is not a gradual process, it happens immediately, at a particular point in time. The main reason for the suddenness of this shift by the LEA is because this investigation is concerned with children, all of whom have physical disabilities. Therefore, the process whereby parents visit LEA special education schools is short – the school is within the borough in which the family resides, and caters for children with physical disabilities. Parents' choice is limited and the shift from covert regulation (through mass schooling policies) to overt control (non-agreement with parents' decisions) is swift.

7.5 Parental positioning

The minutiae of the decision-making process for parents has been discussed already (Chapters five and six). The investigation has explored the perceptions of parents on a programme of Conductive Education in order to understand why they choose it (how

they make sense of the decision-making process). There are no hidden agendas for these parents; they are not making this choice because they need 'something' to pour their energies into although, if they did, these parents have certainly demonstrated that the task of enrolling their child on a programme of their choosing would certainly absorb their energies.

Neither are these parents trying to 'normalise' their children through a programme of Conductive Education. These parents don't want their children to just smell the bread to experience France, they want them to be interactive students who will be given the opportunity to learn how to use their bodies and their minds to their full potential so that they can bake the bread. If the full potential of their child does not lead to baking bread then these parents have witnessed that the Conductive Education programme that their children experience will enable their child to enjoy the very attempt to take part in the bread-making. For these parents, the future identity of their child is dependent upon the theoretical underpinnings of the programme of education.

The 'new visibility' of the family which is proposed by Rose (1989) and represents a unit whose privacy is subjected to social powers, forms only a part of the story for these parents. Rose's new visibility represents the regulation and surveillance of the child by agencies of health and education during the course of childhood. The complication factor which the non-conformity of parents represents suggests two layers of visibility. The first is created by the agencies for the purposes of regulation and surveillance. The second is created by parents through non-conformity and this second layer of visibility serves to unmask the first. "Power is tolerable only on condition that it mask a

substantial part of itself. Its success is proportional to its ability to hide its own mechanisms" (Foucault, 1980: p. 92).

7.6 Reflecting on methods

The methods chosen, grounded theory and discourse analysis, were successful in the sense that they achieved their objectives. The application of grounded theory succeeded in bringing order to a large amount of data so that an interpretation of 'what was happening' could emerge. However, the stringent application of the grounded theory methodology suggested, at times, that certain of the stages mimicked the principle ideas of a quantitative approach. In other words, the substitution of words for numbers, as in the case of identifying properties and dimensions, appeared to be somewhat outside the paradigm of flexible enquiry which qualitative methods are intended to represent. However, the application of latter stages of grounded theory demonstrated a certain strength of interpretation which would not have developed without the structure of earlier stages.

The limitations of grounded theory were identified at the beginning of the investigation and were concerned with the lack of opportunity to engage with meaning, an aspect of enquiry which must be central to gaining an understanding of 'what is going on'. To this end, the application of discourse analysis served to extend the enquiry further by focusing on the main discourses identified through the application of grounded theory. For this investigation, the two methodologies chosen were complementary to one another. Reflexively, however, there are two limitations which could be applied to discourse analysis in this study. The first is that the sheer volume of the data prevented the application of the earlier stages of discourse analysis as well as the issue that the

data, in a sense, represented only one version of events. However, parents as representing only one version of events can only be accepted if viewed reflexively. At the beginning of the enquiry, the participants represented individual versions of events; parents represent a particular culture and hence are representative, collectively, of an event that is common to all (generally rather than specifically). The second limitation represents the linguistic principle of discourse analysis or, more specifically, the reporting of analysis linguistically. The language used to report has to be chosen therefore creating the possibility of choosing words which themselves could impact upon the meaning allocated to the discourse through analysis. The parallel reflexivity techniques addressed this limitation (if indeed it is a limitation) to a certain extent. However, there is a danger that this technique could either perpetuate the linguistic allocation of meaning or end up as an exercise in justification of linguistics rather than a particular technique of reflexivity.

The application of each of these methodologies has resulted in a sense of extreme responsibility because of the interpretative nature inherent to both. This sense of responsibility is not due to a subjective pressure to 'get it right' because the very use of these methodologies suggests a non-acceptance of any universal 'truth' on the part of the researcher. The responsibility appears to be linked to the subjective matter and can best be illustrated through the information (rather than the data) accumulated with regard to this study but not categorised; and data that is rich but represents surrounding issues rather than the central themes (as represented by the title of the thesis).

However, when reflecting on methods, the question must arise concerning whether I would carry out the investigation in the same way with the benefit of hindsight. It is possible that, with the knowledge now to hand, I would choose to work more with

discourse analysis but this is purely as a personal preference rather than as a reflection on the other methodology involved, grounded theory. It is also possible that the parallel reflexivity that occurs in chapter six for the purpose of addressing issues of writer construction (also discussed in chapter six) could have been adopted earlier in order to offer a further measure of clarity when moving from the application of one methodology to another. With regard to the procedure of carrying out the interviews, however, eventhough the criteria for evaluating a qualitative study such as this is not through avenues of validation, it would, nevertheless have been useful to the study to have returned to the participants for a second interview in which to confirm or amend issues raised earlier. However, as already discussed in chapter four, an opportunity was provided by participants for telephone contact and use was made of this supplementary element of enquiry where appropriate.

7.7 My journey through the research process

At the outset, it was my intention to create a balance in my manner of enquiry between my objectivity on the one hand (researcher, lecturer in education and psychology, vice-chair, primary school governing body) and subjectivity (parent with awareness of a nation-wide tendency to deliver the national curriculum at all costs) on the other hand. A sort of neutral ground that held neither objectivity nor subjectivity as it's motivator. The debate surrounding the position of the researcher involved in qualitative enquiry suggests that it is not possible to gain access to personal information unless the tensions between researcher as person are resolved (Harry, 1996). In this sense, becoming the voice of the participants through an interpretation of their discourses occurred naturally through the process of the research. Through the process of reviewing the literature and meeting the parents it became clear that it was necessary for me to acknowledge a

position. This position was one where my vulnerable self as proposed by Ellis (1999) could not, and indeed should not, be denied. My position was one of empathy – not patronising in the sense of sympathising with any abnormal(ness) of a disability. This empathy was concerned with the powerlessness experienced by parents. I became acutely aware of the discourses that serve to drive this powerlessness and whilst they are centred around the enrolment of a child on a programme of Conductive Education, they are, nevertheless, as a result of the historical and contextual construction of disability and special educational needs discourses.

Any expectations of experiencing confusion in my role as researcher because of the power struggles between families and LEAs did not in fact occur because I identified with the families more so than with the position of the LEAs. However, during one interview my position as person rather than researcher seemed to be not accepted. This instance caused me to ponder on the appropriateness (or not) of research into issues of disability being undertaken by non disabled investigators. Although Duckett (1998) suggests that restricting disability studies in such a way could result in sustaining the practice of segregation through identification of the 'other' (disabled/non disabled) discourses and I agree with this point. Further evidence is implicit through my acceptance as person (vs researcher) in all other interview situations.

Of course, in identifying with the participants I could have been laying bare my position to criticism of being too subjective to be able to carry out any useful analysis. This then returns to the point of the necessity to acknowledge a position if seeking personal information. In this way a position that is closer to the participants could (and I feel this is the case) offer insights which would otherwise have been missed as

suggested by Shakespeare (1996) who considers it inappropriate to adopt the role of disinterested observer and views independent research as a fiction.

A further point in relation to my journey through the research process and the issue of my position in the enquiry concerns the purpose of the research. At the beginning of the investigation the research represented, to me, the opportunity to carry out a scholarly piece of work which could be accredited as such through the award of PhD. At that point in time my understanding of the 'scholarly(ness)' of my work was through the historical framework of the university system which Barnes (1996a) has argued perpetuates the notion of objectivity as scholarly through the encouragement of research that is "unfettered by the mundane demands of everyday life." Following on from the interviews with parents my purpose for carrying out the research changed. I still sought the accreditation of PhD but realised that objectivity did not necessarily represent scholarly and that instead of the role of critical theorist in which I had begun the enquiry, I had become instead a critical realist.

My position had to change if I was to become proud of the fact that I had been *involved.* I have been involved in real world research and I do not view my thesis as the starting point mainly because the area of enquiry does not fit neatly into one particular sub-discipline, it is representative of developmental, cognitive and social psychological issues and whilst all of these issues have been included in the process, they now need teasing out separately for presentation to the public domain.

Ultimately, my goal is for these findings to be used to inform policy to address the powerlessness that parents experience. My final position is one of collaboration but not between the University of Wolverhampton and The National Institute for Conductive

Education – but with parents - parents who have chosen Conductive Education and still need to justify their choice for further funding, parents who have yet to choose Conductive Education and those parents who could not face the expected battle.

7.8 Selective interpretations: the research setting

"Trouble awaits those unwary souls who believe that research flows smoothly and naturally." (Hodgon & Rollnick, 1989: p.3)

The data reported in chapter five was based on interviews with participants and the context in which the interviews occurred often impacted upon the positioning of the researcher. This is not intended to suggest any distortion of events on the part of the researcher due to any dissimilarities with the participants (Bhavani, 1990; Griffin & Phoenix, 1994). Rather, it is possible that the dissimilarities were few (researcher as parent interested in issues of childhood disability). A certain acceptance of the researcher into each setting appeared to be implicit through several events which occurred, naturally, during the collection of data.

In one setting, when the interview was underway, the family pets escaped from their garden. The timing of the interview, late afternoon in the winter months, meant that swift action was necessary to track down the errant dogs before all light was lost. Parents set off in one direction and researcher and children in another. Having covered the same ground several times this second group of hunters kept returning to one house in particular and decided to pursue this avenue of enquiry that so persistently manifested itself. The pets had been found by the householder and were safely held whilst they made their own enquiries. Researcher, children and pets returned and the interview was

resumed. The point of including this information is that the tone of the interview had changed since the search had ended. The interviewer was no longer a stanger,welcomed into the setting for the purposes of research. The interviewer had become, within the space of 40 minutes, almost a family friend, accepted into the fold. So, the question arises as to whether this familiarity is advantageous as the family may have been more forthcoming in their dialogue, or disadvantageous because the researcher's subjectivity had been enhanced. For this investigation, bearing in mind the sensitive nature of enquiry, it is held that enhanced subjectivity is seen as a strength of the study rather than a weakness. [As an aside to the story, the role of the family friend was further enhanced by one of the pets regurgitating the contents of his stomach during the interview process – hopefully because of excitement and not as a general comment?].

There are three further incidents where naturally occurring events during the interview setting created a different relationship between researcher and participant. In one setting, during the taped interviews, a child expressed a liking to the interviewer's boots and desperately needed to have them on her feet. The majority of the interview was carried out with the researcher barefoot which could constitute a certain familiarity within the researcher/participant relationship.

In two of the settings (including the one above), the focus of attention for the children present was the equipment used – a cassette audio tape recorder and a microphone. During these instances the tapes are interspersed with snatches of song and nursery rhyme. It is possible that many researchers would feel that the only way to conduct interviews is in as clinical a setting as possible. However, it is also possible and, more likely probable, that the relaxed nature of the settings described herewith produced an

openness which would otherwise have been absent. Barnes (1996a) suggests that the preoccupation that many academics have with objectivity and the never-ending debate about value freedom restricts the audience to academics. It is argued that engagement rather than objectivity may enable the areas of interest of this study to be available to all those it concerns.

7.9 The ethics of childhood disability enquiry

Not all of the naturally-occurring elements of familiarity within the interview setting were as entertaining as those already mentioned. For many of the participants, recalling their stories caused a great deal of anguish. One participant in particular became so distressed at one point that she cried. This did not appear to cause any embarrassment between researcher and participant, rather, a sense of an emotion shared. At the end of this interview, however, and maybe because of the shared emotion, there was an almost tangible sense of separateness – the researcher, having researched, returns to a separate domain; the participant doesn't change; the story by the telling of it, positions the participant as permanently within the parts of the story that cause her anguish.

Finally, but perhaps most importantly, is the feeling of incompleteness with regard to the reporting process. This feeling is caused mainly by the constraints imposed by the title of the thesis. These constraints have resulted in what the researcher considers to be rich data being excluded from the study because they are not concerned specifically with the research question.

The most pronounced area of rich data loss is located in the pilot study or orienteering exercise. During this part of the investigation, as stated earlier, members of a family unit

who had experience of Conductive Education in Hungary and at the National Institute, mainstream schooling and special education provision, agreed to take part in the study. The family unit consists of mother, father, adolescent child with cerebral palsy and young adolescent sibling. The opportunity which arose but which does not fit the remit of the title did so because of the fact that the child in this family unit had experience of several programmes of education and was of an age to be able to assimilate, evaluate and describe the essence of each. Whilst this element may, in the future, form a separate and distinct area of further enquiry, the main points which arose are included here. The reason for their inclusion becomes transparent after their telling.

I will assign the name of John to this participant to protect his anonymity and to remove the impersonal impact of 'the child' although the family are keen to have their story told. The main points which arose from talking with John do not deal specifically with Conductive Education (hence their exclusion) but are nevertheless related to it. Although John is what he and his parents describe as severely disabled, he became independent during his experience of Conductive Education at the National Institute and had a certain amount of mobility. One of the most striking aspects of Conductive Education which John and his parents believe he learned through Conductive Education was his problem-solving skills which they each describe as being transferable to any task.

John moved from the National Institute to a mainstream school and the school was presented with all the facts pertaining to John's abilities. However, John was not allowed to continue with the skills he had learned through his programme of Conductive Education and neither he nor his parents were allowed to be partners in his programme

of education at mainstream schooling. After having learned to be an active participant in his environment and programme of education John was required to be passive. John was not allowed to be mobile and he was not allowed to eat a hot lunch because there was no assistance available – he had to bring sandwiches from home. [Some years later John told his parents of a day when he accidentally spilled a drink over his lunch and *was given, instead, a piece* of bread and butter]. John was not allowed to be assisted to and/or on the toilet which resulted in him reaching home soiled at the end of each day. He arrived home and he had a bath; he would repeat to his parents "you've got to do something about this, you've got to sort it out." His parents report him becoming emotionally distressed at this time. John's parents weren't listened to, they were ignored and labelled as trouble-makers. John was excluded from the national curriculum, he wasn't allowed to swim and he wasn't allowed on school trips – his parents weren't informed of them.

John became very angry when he retold a part of his story which related to his recent experiences in LEA special education provision.. John wanted to know why he was required to be strapped into a standing frame several times a week for an allocated length of time. He wanted to know because the procedure made him faint. The procedure followed is that John is trapped into a standing frame and stands. A visit to a general practitioner failed to ascertain the reason for the fainting and so the procedure continued. Research into the aims of the standing frame revealed that the equipment and the procedure are intended to offer a different position for the physical body and internal organs for people who spend the majority of their time sitting in a wheelchair. John is an adolescent who has been forced into powerlessness which appears to be all the more acute because of his previous learning experiences and abilities. John says

that he cannot discuss anything with the Headteacher anymore because he has been labelled as a troublemaker.

In conclusion, the non-conformity of parents discussed earlier appears to apply also to children under these circumstances. There appears to be a vision of the ideal child present in the special education sector to which John does not conform. The data related to John is presented in an unanalysed form to represent a further responsibility inherent in interpretative techniques – the collection of extremely valuable data that does not fit the remit of the research question. It is presented here for just that reason - I have heard it; it does not fit the title of the research, but it needs to be said. I forgot to ask John if he is allowed to smell the bread, and now I wonder.....

Finally, a rather unencumbered view of what constitutes 'disability' is offered by a ten year-old boy. According to Mark, we are all of us disabled in one way or another. As an illustration of his point, he views me as disabled because I cannot do hand-stands[2] and he can. He further suggests that there are probably 'things' that I can do but which he cannot do and that in this sense we all have a uniqueness.

[2] I can!

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AS/JPD

Mr & Mrs [redacted]

Dear Mr & Mrs [redacted]

I am writing to ask whether you would consider helping in a small investigation that we are making.

We want to document what are the benefits of Conductive Education expressed by the families of young children with cerebral palsy. We are beginning with the families of children who presently attend the Nursery. Later we shall ask families who bring their children to other services here.

We are doing this to help indicate to officials and professionals the sorts of things that people value from Conductive Education - and the problems that they face in getting it. We shall also be bringing the findings to the attention of Government.

This investigation is being done in conjunction with Wolverhampton University which has provided a full-time researcher, Moira Owens, to work on it. All that is required is for you to talk freely to Moira on the subject of Conductive Education and your family's experiences of it. What you say will be tape-recorded but *your contribution will of course be entirely anonymous*. I expect that the interview will take around an hour to an hour and a half.

If you are willing to take part in this, could you please tear off the slip attached and return it to me in your home-school book. Moira will then telephone you, explain more if you wish and arrange to meet at your convenience.

Best wishes

Yours sincerely

Andrew Sutton
Director

I am agreeable to Moira Owens' phoning me to arrange to talk about our experiences of Conductive Education.

Name .....

Signed .....

Date .....

EDITORIAL

CONDUCTIVE EDUCATION ASSESSED

FROM Her Majesty's Stationery Office come Parts I and II of a Final Report of the Evaluation of Conductive Education for Children with Cerebral Palsy[1]. It is a somewhat startling event. For the benefit of colleagues abroad who have not heard of the Peto Institute and conductive education, it is the equivalent of the United States Government deciding to back a research project to compare the Doman-Delacato Institute of Human Potential with standard programmes in North America, or the German Government carrying out a similar exercise with Vojta's system of treatment so widely espoused over Southern Germany and Northern Italy. But this is what the UK Government has done: largely as a result of parental and media pressure, it has spent some money on this research and more money on supporting conductive education both here and in Hungary itself, at a cost to others who would like to have had a little more money themselves to develop their care of disabled children. Intense media promotion led to the belief that in Hungary something was on offer for children with cerebral palsy that was far better than anything we had on offer in the United Kingdom.

Briefly—and do read it for yourself—the study reports on 19 children who went through the new Birmingham Institute for Conductive Education evaluated against a comparison group sufficiently far off to be uninfluenced by the goings-on in Birmingham (namely Manchester) who went through 'traditional' English special education. The research team from the Univesity of Birmingham School of Psychology had four aims: (1) to establish whether what went on in Birmingham replicated what went on at the Peto Institute in Budapest; (2) to try to glean some understanding of the principles on which conductive education works; (3) to compare the effectiveness of conductive education against traditional British programmes; and (4) to see whether conductive education should have wide application in the UK.

Their conclusion was that it should not, because there was no real difference between the two groups at the end of the two-year study—if anything, the Manchester group did better: 'The Manchester group made better progress than the Birmingham group on one direct test of cognition, one direct test of fine-motor functioning, two direct tests of gross-motor functioning and one indirect test of independence in daily living skills' (Part I/6.8.2.4, p. 46). Perhaps more importantly (because I hope most of us clinicians worry about the hips all the time): 'There was a deterioration in the mobility of the hips in the group receiving conductive education, but there was no such deterioration in the Manchester group' (ibid.).

The methodology that was employed is extensively discussed: some of the tests used to assess the groups were norm-referenced, some were criterion-referenced. The investigators looked at the scales that the conductors used when assessing the children, and they also looked in detail at the selection process used to identify the best candidates for conductive education (already published in this journal[2]).

A meeting held to launch these reports did not lead to a particularly profitable discussion, and it is perhaps worth identifying one or two of the reasons for this. First, some parents present (who had been at the Birmingham Institute) strongly felt that the method *had* benefited their child, and it is always puzzling for parents as to why we professionals do not take their word for this. The answer is quite simple: I have on file

letters from, and have spoken to, parents who have told me that everything from Bach Flower remedies to processes used by the Institute of Human Potential in Philadelphia—or indeed, on occasion what is sometimes referred to as 'conventional medicine'—have benefited their children enormously. That is good, and, to any parent who feels that a particular type of therapy is helping their child, the sensible advice—provided one is happy that the child is not actually being harmed—is for them to pursue that course of treatment. But this does not mean that the professional should recommend it to other children while there is no objective measure that it works.

Second (and this applies not only to conductive education), enthusiasm and hope exert major influences on children and their families. Without these vital factors, no therapy or education will work, but—and this is my third point—this is often because in the real world run by governments, services for children with disabilities are hard even to maintain, let alone develop, and we know from the Oregon studies that the general populace would not spend much money on disabled children, so this is something we continually have to fight.

Of course, supporters of the Peto system have called 'foul'. They have complained that the study did not really reflect conductive education and that circumstances at the time of the study were difficult for the Birmingham Institute, although I bet you that the special schools in Manchester who provided the comparison group were having their share of problems during the last three or four years with maintaining staff, staff morale and a good service for their parents. It is hard to know whether Dr. Harti from Budapest or Andrew Scrutton, representing the Institute of Conductive Education in the UK, really believes that if a further study were carried out or pursued longer a more positive result for conductive education would emerge. It seems to me unlikely.

When disability emerged from the equivalent of the Dark Ages, there were a number of innovators who attacked the issue of helping these children very vigorously: one can mention the Bobaths, Phelps, Sister Kennie, András Petö himself and, if you like, Vojta as people who made a contribution to the care of children with cerebral palsy. But we are past the age of the innovators, and are now trying collectively to develop a real understanding of the nature of cerebral palsy and how best we can help the sufferers.

It would be very surprising if researchers in Edinburgh (Brown, Minns and Lin, for example) who have built on the earlier work of an innovator (Ingram[3]) were not contributing to our knowledge of both the nature and management of cerebral palsy. It would be surprising too if Peter Rosenbaum's group at McMaster in Canada, doing so much work on measurement and assessment, or Bleck's deep knowledge of the orthopaedic aspects of cerebral palsy, were not useful; or if Tardieu's group in Paris and Mercer Rang's group in Toronto had not (as we know they have) made useful contributions to our understanding of contractions. And I am unfairly picking out only a few of those people who are contributing to our knowledge of cerebral palsy.

What we want now from advocates of particular systems of therapy is an acceptance that they can be only a part of the whole and that their task is to develop objective scientific data on their innovative ideas, which we can then incorporate into the growing body of knowledge of cerebral palsy. Only they will we have some feeling as to what is best for children with cerebral palsy and the other related developmental disorders.

I have of course mentioned here largely health-related workers, but in the field of special education, too, many are trying to see what really does work for the child and what does not. Could we not, as Scrutton[4] argued some time ago now, leave behind the systems of therapies and advance on a broader front to develop effective means of helping the child with cerebral palsy?

MARTIN BAX

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H.M.S.O. should have made clear that Part I is a summary of Part II: Part II gives the detailed data. If you are going to read Part II, you do not need to buy Part I.

Editorial

A treatment that works

Much has been written about the problems a professional has in conveying bad news to families about their child with a disability. Disclosure has been the subject of research, and useful information is available to the practitioner to help in this difficult task. However, there is far less literature, as far as I am aware, on the problem of discussing treatments with parents, although this, too, can be very difficult. I recently spent a good hour with a family discussing a possible line of treatment for their child, talking about the logic – or lack of logic – of the treatment method proposed. We seemed to agree that there wasn't really any basis for their child to have the treatment. I was somewhat taken aback, however, when the interview ended and the family said, 'Well, we're going to do it anyway'. The proposed treatment, incidentally, would give the child initial discomfort and involve him in dietary treatment which I felt certain – as certain as one ever can be – would not be effective.

There are all sorts of landmines for the unwary, one of which I've stressed before: the use of the words that come up in these situations, such as 'treatment' and 'therapy'. More than one parent has told me that when offered therapy they assumed that this meant their child with cerebral palsy would 'get better'. It is very important for therapists and doctors to make it clear that what they are offering is a management procedure. Of course, that management procedure may lead to an apparent cure; the late-talking child who has effective speech therapy will start talking. But one may be left wondering whether one has simply brought on a late development and left untouched the child's central nervous system impairment that may have an impact later on. So the edges between treatment and management are blurred. But, on the other hand, in the work we do with physical therapy and cerebral palsy we are not going to achieve a cure although our activities will, we hope, prevent things like dislocation of the hip. Is that a treatment?

In thinking of discussions with parents, there are two types of proposed 'treatment' that one must be clear about. The first is where a treatment might be potentially harmful: a medication that won't work and has significant side effects. Here one can be very firm in refusing to recommend such a treatment, but then what? There are the physical treatments to which many children are exposed that can cause pain. I find it hard to believe that a treatment which leaves a child in deep distress – screaming repeatedly – can have anything but negative effects.

So I have two firm criteria – harmful treatments and those that are distressing to the child – where I will be quite dogmatic in the statement of my views. But beyond that there's a whole range of things that may happen to the child which do not fall into my two categories, but nevertheless I feel uneasy about. This unease may be on two grounds. The first is when a child is denied some pleasure. If a diet is recommended which excludes, say, chocolate, one of the pleasures of childhood – and adult life – is taken away, and that should be considered. Second, and more worrying I think, is the way therapy may deeply affect a child's day-to-day life. In one country I found that the children went to school from 8 am to 2 pm and after their break and required rest they had therapy from 3 o'clock until the end of the day. Similarly, many families who indulge in types of therapy beyond that proposed by their professional team expose their child to these treatments from the moment they get home from school or centre, leaving no time for that essential component of childhood, play[1]. Why do parents behave this way? One answer lies in the notion that they are living in an unresolved bereavement concerning the loss of the hoped-for 'normal' child who never was, they find it difficult to be objective in evaluating information about treatment and are more prone to shop around and grasp at straws[2].

These are some of the problems that fill my mind as I start the difficult consultation over what can be done for a child with severe neurodisability. Perhaps where the findings have been negative, say in an autistic child when we have told the parents that the brain looks normal and they can perceive no other defects in their physically attractive child, the feeling that there must be a cure out there is enormously powerful. In the end perhaps it is not only the parents who begin to clutch at straws, but sometimes clinicians themselves. I am not implying that the paper by DeLong et al.[3] in this number is clutching at straws, merely admitting – as do the authors – that it is an uncontrolled trial. One would stress, just as the authors do, the need for controlled trials before using the medication suggested. There are theoretical reasons why this treatment might work and all our referees recommended we publish this paper. We hope that others will immediately move to controlled trials and that we shall shortly be better placed to help parents of children with this particular brand of neurodisability, with a treatment that works.

Martin Bax

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PARENT

SPECIAL EDUCATIONAL NEEDS TRIBUNAL

Presenting your case to the Tribunal

Summary information and Guidance with the Authority's Reply

At the hearing the members of the tribunal will want to make sure that both you and the Local Education Authority (LEA) whose decision you are challenging have a chance to explain your points of view fully.

The members of the tribunal will want to find out from both you and the LEA: -

- what you think are the relevant facts?
- what conclusions you think the tribunal should draw from them? and, above all
- what you think should now be done in the interests of the child?

The tribunal chairman will make the procedure as informal as possible in order to help everyone express their point of view. For example, he or she will suggest that different aspects of the case are dealt with one at a time, rather than asking either you or the LEA to make a statement about the whole of the case. Taking each aspect of the case in turn will give everyone the opportunity to concentrate on points as they come up, without getting muddled. Generally, the chairman will first ask the representative of the Authority to explain the LEA's view on each point, and then ask you to explain yours. Any evidence from witnesses on the point will be heard in the course of the discussion of that point, and both parties will be able to ask questions about it. Witnesses will normally be present throughout the hearing.

The discussion at the tribunal hearing need not be limited to the points the chairman raises. The chairman will give you the chance to add anything which you feel is important, but has not been mentioned. It may be a good idea to make a list, in advance, of what you would like the tribunal to consider. You can then tick the matters off as they are discussed, and at the end bring up any which were left out.

PARENTS' VIEWS

*** Please read the accompanying letter before filling this in ***

1. Do you feel your child has difficulties? What do you feel they are?

   You may wish to say what he is like at home or in other places, or whether there are any medical difficulties, for example.

2. What has been tried so far?

   If your child has had any special help either at home or at school, you may like to mention it here.

3. What is your child good at?

   Does your child make friends easily? Has your child any special interests?

4. What might be useful in the future?

   Here you can tell me what you think would help your child in the future.

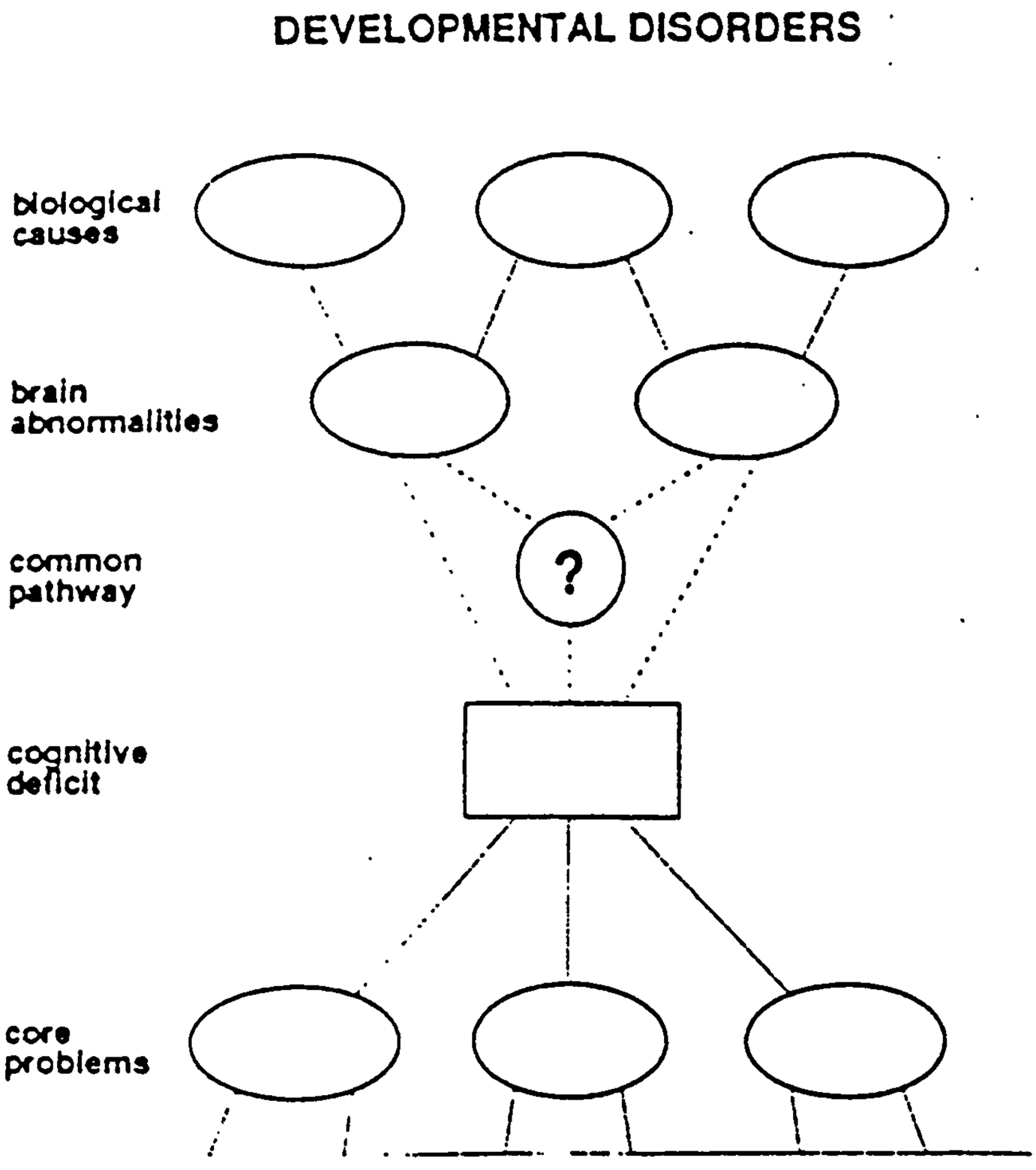
Child's Name . . . . . Signature

Date of Birth . Date

School .....

Please return to: AEO, Special Needs (South Area)
Education Department, Margaret Street, Birmingham B3 3BU

APPENDIX VI



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EDUCATION DEPARTMENT

MEDICAL REPORT ON A CHILD WHO MAY HAVE SPECIAL EDUCATIONAL NEEDS

This report will be submitted to the Education Department as part of the Assessment of the child's Special Educational Needs. Therefore it is important that the content of the report is fully discussed with the child's parents or carers.

Health District of Residence _____

Health District Completing Advice _____

SURNAME OF CHILD _____ OTHER NAMES _____ SEX ___

DATE OF BIRTH _____ PRESENT PLACEMENT _____

NAMES OF PARENTS/GUARDIANS _____

CHILD'S HOME ADDRESS: ADDRESS: (if different from home address)

_____ _____

_____ _____

Language spoken in the home (if English not spoken fluently) _____

Say if English spoken/read/written by father _____

Say if English spoken/read/written by mother _____

If an interpreter was used, state who this was _____

SIBLINGS AND PLACE IN THE FAMILY: (Tick for subject and ring as appropriate for others)

1	2	3	4	5	6	7	8	9	10
M F	M F	M F	M F	M F	M F	M F	M F	M F	M F

General Practitioner:

Other professionals involved: Tick if report attached/requested

_____ ☐ ☐

_____ ☐ ☐

_____ ☐ ☐

_____

Signature of doctor: _____ Date of report: _____

Name of doctor (print): _____

Designation: _____

Address: _____

_____

Telephone: _____

Copies to:
Psychological Service
North / Central / South

Special Needs
North / Central / South

DATE OF EXAMINATION:

1) PAST MEDICAL HISTORY - of relevance to the child's Special Educational Needs.

In all areas, indicate if statements based on direct examination or report by the parent or others.

2) PHYSICAL HEALTH AND RELEVANT FINDINGS ON EXAMINATION
(including medication, allergies and immunisation status)

3) VISION:

		Right	Left
Visual acuity unaided	- distance		
	- near		
aided	- distance		
	- near		
Colour vision			

Additional comments and inplications for education:

Is the child registered blind or partially sighted?

4) HEARING:

Audiometric test: Date: _____ Result: _____

Additional comments and inplications for education:

5) SPEECH AND LANGUAGE:

6) MOTOR FUNCTION:

7) SOCIAL BEHAVIOUR AND EMOTIONAL DEVELOPMENT (including self-help skills)

MEDICAL ADVICE:

8) List below any medical difficulties outlined above which may affect the child's education:

SPECIAL DIFFICULTIES: RECOMMENDATIONS, IMPLICATIONS AND ADVICE:

9) VIEWS OF THE CHILD, IF ELICITED:

10) ANY OTHER RELEVANT COMMENTS OR INFORMATION:

Education Department

Psychological Service (South Area)

Our Ref. AEE/SAM/F10/2 **Date: 03.02.97**

STATUTORY ASSESSMENT : PSYCHOLOGICAL ADVICE

Psychological advice is requested under the statutory procedures specified in the Education Act 1993, and in the Education (Special Educational Needs) Regulations 1994.

Child's Name : **Sex :**

Date of Birth : **Age :**

Child's address :

School : **Year:**

Parent(s)/Guardian(s) :

Parent's address (if different) :

Home language(s) :

PART 1: INITIAL INFORMATION

1. Sources of information

2. Any relevant background information

Family

Physical/Medical

Agencies Involved at Present

PART 2: SPECIAL EDUCATIONAL NEEDS (LEARNING DIFFICULTIES)

3. Factors (if any) which may have affected the child's progress and development

4. Child's skills and attainments - General summary and conclusions

If considered necessary, an appendix can be attached, giving more detailed information of the Psychologist's assessment and the actual performance of the child (e.g. on standardised tests).

Language

Play and Activities

Self-help Skills

Gross Motor Skills

Fine Motor Skills

Summary

5. List of child's special educational needs

PART 3: SPECIAL EDUCATIONAL PROVISION

6. Summary of special educational help the child has received and is receiving currently

7. Main educational and developmental objectives which the special educational provision should aim to meet

8. Recommended special educational provision to meet the stated objectives

Curriculum

Facilities and Equipment

Human Resources and Support Services

Group Size

Attendance

9. Arrangements required for monitoring and evaluating the child's progress

PART 4: PLACEMENT

10. Recommended placement to meet the child's special educational needs

The Psychologist is reminded that, under section 160 of the Education Act 1993, the LEA is under a qualified duty to secure that the child is educated in a mainstream school.

PARTS 5/6: NON-EDUCATIONAL NEEDS & PROVISION

11. Any other, non-educational factors, that the LEA should consider

VIEW OF PARENTS & CHILD

12. Current views of the parents/guardians

13. Current views of the child

Advice sent to A.E.O. Special Needs :
Copy to: Parents/Guardians :
Medical Officer :
Head Teacher of Present School :
Other : T.S.

Psychologist :
Position :
Qualifications :

Psychologist's Signature..... Date .....

Please copy this report to Parents, and to the SCMO. Send the original to your area AEO (Special Needs) at: The Education Department, Margaret Street, Birmingham, B3 3BU

CITY OF . EDUCATION DEPARTMENT

STATEMENT OF SPECIAL EDUCATIONAL NEEDS

PART 1 : INTRODUCTION

1. In accordance with section 168 of the Education Act 1993 ("The Act") and the Education (Special Educational Needs) Regulations 1994, ("The Regulations") the following statement is made by the Birmingham City Council ("the authority") in respect of the child whose name and other particulars are mentioned below.

Child

Surname ..... Other Names .....

Home address .....

.....

.....

Sex .....

Date of birth ..... Religion .....

Ethnic Origin..... Home language.....

Child's parent(s) or person(s) responsible

Surname ..... Other names .....

Home address ..... Relationship to child .....

.....

Telephone No .....

2. When assessing the child's special educational needs the authority took into consideration, in accordance with regulation 10 of the Regulations, the representations, evidence and advice set out in the Appendices to this statement.

PART 2: SPECIAL EDUCATIONAL NEEDS

PART 3: SPECIAL EDUCATIONAL PROVISION

- which the Authority considers appropriate to meet the needs specified in Part 2.

1. Objectives

2. Educatical provision to meet needs and objectives.

Educational Provision (continued)

3. Monitoring

PART 4: PLACEMENT

PART 5: NON-EDUCATIONAL NEEDS

PART 6: NON-EDUCATIONAL PROVISION

(Date) .....

.....

Assistant Director
Special Educational Needs
Authorised Officer

(see overleaf for list of attachments)